SUBJECTIVE QUALITY OF LIFE FOLLOWING TRAUMATIC BRAIN INJURY

Matthew Thomas

B. Soc. Sci. (Welfare), Grad. Dip. Couns.

School of Psychology

University of Tasmania

Submitted in partial fulfilment of the requirements of the degree of

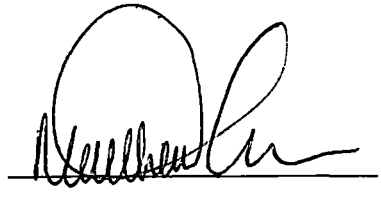
Doctor of Philosophy in Clinical Psychology

at the University of Tasmania, 2008.

Statement of Authentication and Authority of Access

I certify that this thesis does not contain any material previously submitted for a degree or diploma at any University, and that to the best of my knowledge it does not contain any material previously published or written by another person where due reference is not made in the text.

This thesis may be made available for loan and limited copying in accordance with the Copyright Act 1968.



Matthew Thomas

July 2008

ABSTRACT

Traumatic brain injury (TBI) can cause impairment of functioning, that disrupts critical aspects of psychosocial functioning such as work, interpersonal relationships, and participation in recreational activity (Jennett, 1997; Seibert et al., 2002; Tate, Lulham, Broe, Strettles, & Pfaff, 1989). As such, TBI affects the quality of life of those who suffer its ongoing effects (Ponsford, Sloane, & Snow, 1996; Tennant, Macdermott, & Neary, 1995). Although many TBI rehabilitation services state their aims as being to optimize quality of life following injury, there has been very little research in this area. Reasons for this include ambiguity in conceptualisation of quality of life and lack of consensus about appropriate measures. Building on recent international consensus group recommendations (e.g., Bullinger, 2002; National Institutes of Health [NIH], 1999), this thesis addressed some fundamental gaps in knowledge in the TBI/QOL field.

This project aimed to provide an understanding of SQOL outcome and ultimately develop predictive models of SQOL outcome following TBI. The project utilized outcome data from a large population-based sample, collected prospectively by the Neurotrauma Register of Tasmania. In summary, Study 1 identified an appropriate measure of subjective quality of life (SQOL), Frisch's (1994) Quality of Life Inventory (QOLI) and found it was sensitive and appropriate for adults with TBI. However, no research had been conducted with the QOLI within the TBI population.

Study 2 confirmed a three-factor structure for the QOLI using both exploratory and confirmatory factor analysis and identified only subtle differences between the US-based normative distribution and pre-injury

estimates of a sample of 470 people with TBI. Study 3 reported SQOL outcome over four time-points to 12 months following injury for the QOLI Total and QOLI Factor scores with a sample of 663 participants. Significant deterioration was observed in QOLI scores at one and three months following injury, returning to near pre-injury estimates by six months. Study 4 examined outcomes and relationships between a large number of potential predictive variables identified from previous research with QOLI outcomes. A number of important predictive variables were identified across the five domains suggested by Berger, Leven, Pirente, Bouillon, & Neugebauer (1999). Study 5 used regression modeling to confirm predictive models of SQOL outcome at one, three, six and twelve months following TBI and provided a means of identifying those at risk of poor outcome.

This fundamental TBI/SQOL research provides clinicians and researchers with the structure as well as pre and post injury normative distributions of an appropriate measure of SQOL. The predictive models produced by this analysis explained more variance than models reported in previous research, correctly predicting participants' SQOL outcome to within a single point in over 70% of cases. The predictive models will be valuable for rehabilitation clinicians who wish to identify people who are at risk of poorer outcome. Building on the results of this project, there are many avenues for further research. These include extending the methodology to predict SQOL outcome over two, five or more years following injury, and developing effective interventions that facilitate restoration of SQOL following TBI.

ACKNOWLEDGMENTS

There are many individuals who contributed to the production of this thesis through their participation in the research, advice and support. I have very much appreciated the careful supervision and encouragement of A/Prof. Clive Skilbeck. The later studies reported in this project were made possible with the assistance of the Neurotrauma Register of Tasmania (NTR), and the support of Dr Mark Slatyer. I am very grateful for the opportunity to have been involved with the NTR and would like to thank the staff and participants. The NTR Brain Injury Outcome project was funded by the Motor Accident Insurance Board of Tasmania. I would also like to thank Dr Iain Montgomery for his review and helpful comments, as well as James Alexander, Dr Alison Bowling and Dr John Davidson (School of Psychology, University of Tasmania) for their support with aspects of the analyses.

My appreciation also goes to Dr Anita Mak, James Neill, and Prof. Paul Morrison (University of Canberra) for their assistance with aspects of the first study. Thanks also to my former colleagues within the NSW Brain Injury Rehabilitation Programme and at Outward Bound Australia, particularly Tracey Goldsworthy, Lloyd Worthy, Ann Smith, Judy Burrows, Annabelle Gibson and Lucie Shanahan for their work in support of the Potential Unlimited Programme. The pilot programmes evaluated in the first study received a small grant from the NSW Motor Accident Authority.

Finally, I would like to express my gratitude to my family and friends for their understanding, encouragement and support over the many years I have been engaged in this research project.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter 11

Chapter 12

Chapter 13

LIST OF APPENDICES

Chapter 5

Appendix R Study 2, 3, 4 and 5 Information sheet

Appendix S Study 2, 3, 4 and 5 Participants' consent form

Appendix T Study 2, 3, 4 and 5 Person responsible consent form

Chapter 6

Appendix U Appendix Tables 6.1, 6.2 and 6.3

Chapter 8

Appendix V Appendix Tables 8.1 and 8.2

Chapter 9

Appendix W Appendix Tables 9.1 to 9.27

Chapter 10

Appendix Y Appendix Tables 10.1 to 10.12

Chapter 11

Appendix Z Appendix Tables 11.1 to 11.7

Chapter 12

Appendix AA Appendix Tables 12.1 to 12.18

Chapter 14

Appendix AB Appendix Tables 14.1 to 14.12

Please note. The data sets and output files for all analyses reported in this thesis are presented for each of the five studies on the Appendix CD. SPSS 15 or later may be required to view these files.

LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statisitcs
APA	American Psychiatric Association
ASCO	Australian Standard Classification of Occupations
CFA	Confirmatory factor analysis
CIQ	Community Reintegration Scale
COWAT	Controlled Oral Word Association Test
CVLT	California Verbal Learning Test
DSM	Diagnostic and Statistical Manual (APA, 1994 and 2000)
EFA	Exploratory factor analysis
FIM	Functional Independence Scale
GCS	Glasgow Coma Scale
GOAT	Galveston Orientation and Amnesia Test
HADS	Hospital Anxiety and Depression Scale
HRQOL	Health Related Quality of Life
ICF	International Classification of Functioning, Disability and Health
LOC	Loss of consciousness
NART	National Adult Reading Test
NHIF	National Head Injury Foundation (USA)
PASAT	Paced Auditory Serial Attention Test

PCS	Post-concussive Syndrome
PTA	Post Traumatic Amnesia
QOL	Quality of life
QOLI	Quality of Life Inventory (Frisch, 1994)
RPQ	Rivermead Post-concussion Symptoms Questionnaire
SF-36	Short Form 36, a measure of HRQOL
SQOL	Subjective quality of life
SWB	Subjective well-being
TBI	Traumatic brain injury
TBI/SQOL	Subjective quality of life following traumatic brain injury research field
VPT	Visual Patterns Test
WAIS III	Weschler Adult Intelligence Scales
WCST	Wisconsin Card Sorting Test
WHO	World Health Organisation
WHO ICIDH	World Health Organisation's International Classification of Impairments, Disabilities and Handicaps

CHAPTER 1

INTRODUCTION AND THESIS OVERVIEW

In the past thirty years advances in emergency medicine have saved the lives of countless people who sustained (TBI). Overwhelmingly, those most likely to sustain TBI are young males involved in motor vehicle accidents and assaults, and older people who experience falls (Fortune & Wen, 1999; Ponsford et al., 1996). In summary, the effects of TBI can impair physical, emotional and cognitive functioning. The effects of these impairments can limit functioning and independence across a range of critical areas of a person's life such as work, interpersonal relationships, and participation in recreational activity (Jennett, 1997; Seibert et al., 2002; Tate et al., 1989). These represent key aspects of most people's well-being and life-satisfaction and are often used by clinicians and researchers as indicators of psychosocial functioning and quality of life (QOL) (Ponsford et al., 1996; Tennant et al., 1995).

Following initial medical recovery and their return to community living, many people with significant TBI struggle to come to terms with their new limitations and to find ways to rebuild purposeful, satisfying lives (Condeluci, Ferris, & Bogdan, 1992; Simpson, 1996). In attempting to meet the needs of the injured and their families, TBI rehabilitation has become a focussed effort aimed at restoring functioning and supporting optimisation of quality of life (Jennett, 1997; MWBIRP, 1999). In summary, subjective quality of life (SQOL) can be equated with life satisfaction and refers to an individual's subjective evaluation of the degree to which his or her most important needs, goals, and wishes have been fulfilled (Frisch, Cornell, Villanueva, & Retzlaff, 1992). Typical domains of

life satisfaction include work, financial status, relationships, leisure activity, and home and community environment.

This introductory chapter outlines a conceptual overview of traumatic brain injury (TBI) with discussion of definitions, mechanisms and incidence of injury. Detailed discussion of outcome following TBI is clarified with the application of the World Health Organisation's model of Impairments, Disabilities and Handicaps (WHO ICIDH-2, World Health Organisation [WHO], 1999). Presentation of definitions of quality of life (QOL), the role of TBI rehabilitation in relation to SQOL and psychosocial adjustment leads to a discussion of the integration of these concepts within the WHO ICIDH model. The chapter concludes with an explanation of the structure of the thesis.

1.1 The present status of TBI/SQOL research

The study of SQOL following TBI is a new and rapidly emerging field (Bullinger, 2002; Dijkers, 2004; Johnson & Miklos, 2002). This important area of research, provides an "insider's view" of their well-being and satisfaction with life following TBI (Berger et al., 1999). TBI/SQOL outcome research has very important implications for the design and delivery of rehabilitation interventions and support. Although it is a new and complex area, the TBI/SQOL field is beginning to provide a body of knowledge about the needs of people with TBI and their perceptions of satisfaction about their lives in the community.

The literature in the TBI/SQOL field includes a relatively small number of studies. Interestingly, several correlational studies have found relationships between SQOL and a number of variables across key domains including aspects such as severity of injury, physical independence, memory and

attention, mood, and social functioning (e.g., Warren, Wrigley, Yoels, & Fine, 1996; Webb, Wrigley, Yoels, & Fine, 1995). However, the TBI/SQOL body of knowledge has been limited by many studies relying on cross sectional designs, frequently with small samples, at various points in time following TBI (e.g. Kalpakjian, Lam, Toussaint, & Hansen Merbitz, 2004).

Out of the establishment of this preliminary base of TBI/SQOL research has come recent calls for consensus and greater focus for future research efforts. For example, in a comprehensive review of 16 studies published since 1991, Berger et al. (1999) found basic inadequacies in this field of research included an absence of consensus on the conceptualisation of quality of life and a lack of SQOL instruments validated for use within the TBI population. These authors also noted previous outcome studies had not utilized measures covering an adequate range of domains affected by TBI, and found assessments of outcome have varied considerably between studies from three months to 24 years. On the latter issue, Bullinger (2002) provides guidance indicating assessment of outcome should most usefully proceed during the acute phase/hospital recovery (3 months following injury), in the phase of rehabilitation (at least 12 months after trauma) and recommends further repeated assessment.

1.2 The focus of the present research

Given the early stage of development of the TBI/SQOL field, there was an absence of predictive models of SQOL functioning following TBI. Whilst attempts have been made at developing such models, there have been a number of serious limitations with these studies. In summary, modeling research first

required validation of an appropriate measure of SQOL within the TBI population. In line with recent international consensus group recommendation, the present research was based on a large prospective sample of people with TBI, utilised a comprehensive array of relevant variables, and was conducted at appropriate time intervals following injury (Berger et al., 1999; Bullinger, 2002; Dijkers, 2004; Johnson & Miklos, 2002).

The identification of predictive models of SQOL following TBI represents an important contribution to the body of theory and knowledge in TBI outcome research. It provides clarification of the valence of an array of variables affecting SQOL outcome, and suggests routes to effective rehabilitation interventions. The validation of an appropriate measure of SQOL within the TBI sample supports the use of such a measure in quantifying valued outcomes in rehabilitation contexts and the broader field of TBI outcome research.

1.3 Background to traumatic brain injury

TBI has become a major cause of disability amongst western nations (AIHW, 2007; Berger et al., 1999; Fortune & Wen, 1999; Jennett, 1997). TBI can have devastating effects for survivors who suffer functional impairment and poor SQOL, whilst their families are often burdened with providing ongoing care (Berger et al., 1999; Ponsford et al., 1996). In an international attempt to understand and remedy these problems, TBI outcome and rehabilitation research has become a distinct field within the medical and allied health professions.

1.3.1 Definition

Definitions of TBI are relatively consistent across countries (Fortune & Wen, 1999). The definition used in this project was provided by Ponsford et al. (1996) who cites the definition of TBI used by the National Head Injury Foundation (NHIF) in the USA as; "an insult to the brain caused by an external force that may produce diminished or altered states of consciousness, which results in impaired cognitive abilities or physical functioning" (p. 1).

In summary, TBI may result from a blow to the head from a blunt object or from blunt impact of the head with a stationary object. TBI may also result from penetration of the head and brain by a sharp instrument or missile. In industrialised countries, more than 70% of TBI occurs in motor vehicle or other road transport related accidents. TBI may also occur as a result of industrial accidents, assaults, falls, sports and war injuries (Ponsford et al., 1996).

1.3.2 Mechanisms

A number of primary and secondary pathophysiological events have been identified as mechanisms of TBI. Primary injury to brain tissue may occur as a result of acceleration or deceleration forces exerted on the head. This may cause skull fractures producing laceration to the cerebral cortex, cerebral contusion where the brain and skull move differentially causing hemorrhagic lesions, diffuse axonal injury or widespread axonal transection where brain cells are sheared (Ponsford et al., 1996). Following the primary injury, further damage to the brain can be caused by intracranial complications. These are referred to as secondary brain injury and include intracranial haematoma, brain swelling and raised intracranial pressure, infection, including meningitis and/or cerebral

abscess, and anoxia due to reduced blood pressure. Advances in emergency medicine in recent years have increased the effectiveness of treatment of secondary complications of TBI and reduced mortality rates (Ponsford et al., 1996).

1.3.3 Incidence

The Australian Institute of Health and Welfare Research has conducted studies investigating the incidence of TBI in Australia (Fortune & Wen, 1999). This research showed there were 27,437 hospital separations with a primary diagnosis of TBI in the year 1996-1997. Although there was variation between states, the overall rate of incidence was reported at 149 per 100 000 population (Fortune & Wen, 1999).

It is widely acknowledged that persons aged between 16 and 25 are at the highest risk of traumatic brain injury (see Fortune & Wen, 1999). Young men are three to four times more likely to suffer brain injury than young women (Fortune & Wen, 1999; Ponsford et al., 1996). Statistically, the risk of traumatic brain injury decreases as a person's age increases into middle age and then increases at about age 60 to 65 years (Fortune & Wen, 1999; Sorenson & Kraus, 1991). As the life expectancy of people with TBI is unaffected by injury, there is a cumulative effect, with the numbers of people with TBI in the community continually increasing.

1.3.4 Severity of injury

The severity of brain injury is generally determined by the degree and duration of loss of consciousness (LOC) and/or the length of time the patient is assessed to be experiencing post traumatic amnesia (PTA) following head

trauma. Both these indicators of severity of TBI may be measured. Consciousness may be assessed with the Glasgow Coma Scale (GCS), whilst duration of PTA may be checked daily with a variety of scales (Sorenson & Kraus, 1991; Ponsford et al., 1996). Measures of LOC and PTA will be examined separately as follows.

Teasdale and Jennett first published the Glasgow Coma Scale (GCS) in 1974. The scale is widely recognised to define and grade coma. Teasdale and Jennett defined coma as the absence of eye-opening, failure to obey commands, and failure to give any comprehensible verbal response. Responses in each category are ranked and assigned a numerical value, yielding a total score between three (a person showing no response) and 15 (a person who is alert and well orientated) (Ponsford et al., 1996).

GCS scores in the first 24 hours after injury are frequently used to grade severity of brain injury. Scores of three to eight are said to indicate severe injury, nine to 12 moderate injury, and 13 to 15 mild injury (Ponsford et al., 1996). A number of outcomes studies have demonstrated GCS score to be a significant predictor of functional outcome following medical recovery (e.g., Klonoff et al., 1986; Ponsford, Olver, Curran, & Ng, 1995).

The majority of patients rendered unconscious emerge from coma. This occurs over varying periods of time. After regaining consciousness, the injured person typically passes through a phase termed post-traumatic amnesia (PTA). First defined by Symonds (1940), this phase is categorised by generalised cognitive disturbance including confusion, disorientation and an inability to store or retrieve information from memory. PTA is said to terminate with return of

continuous memory. The duration of PTA dates from the time the injury was incurred until the return of a capacity to store and retrieve new information. Several tests have been developed to measure the duration of PTA including the Galveston Orientation and Amnesia Test (GOAT) and the Westmead and Liverpool PTA Scales (Ponsford et al., 1996). The duration of PTA is widely used as a measure of severity of brain injury. Table 1.1 lists the severity of brain injury according to the duration of PTA, LOC and GCS (Ponsford et al., 1996).

Table 1.1

Classification of severity of traumatic brain injury (Russell, 1977)

Severity	GCS	Duration of PTA	LOC
Very Mild	13-15	< 5 minutes	
Mild	13-15	5 to 60 minutes	<30 mins
Moderate	9 to 12	1 to 24 hours	>30 mins
Severe	<8	1 to 7 days	
Very severe	<8	1 to 4 weeks	
Extremely severe	<8	> 4 weeks	

Note. GCS=Glasgow Coma Scale, LOC=Period of loss of consciousness.

There has been debate in the literature as to the utility of the duration of unconsciousness (LOC) and PTA and as predictors of patient's functional and psychosocial outcome. Whilst some authors concluded these variables to be of little use (e.g., Brooks et al., 1986; Tate et al., 1989) a recent, study involving over 500 participants found that the duration of PTA and unconsciousness were a significant prognostic predictor of degree of recovery and quality of life (Asikainen et al., 1998; see also Stambrook et al., 1990).

There has been some disagreement amongst epidemiological studies about the incidence of TBI at the varying levels of severity. The report from the Australian Institute of Health and Welfare (Fortune & Wen, 1999) relies on Kraus's (1987) estimates, which suggest that 80% of hospitalized TBI cases were mild injuries, 10% were moderate and 10% severe.

Australian epidemiological studies by Hillier, Hiller, & Metzer (1997) and Tate, McDonald, & Lulham (1998) provide local evidence of incidence of severity of injury. Hillier et al., (1997) reviewed statewide hospital separations from a major teaching hospital in South Australia for the 1987calendar year. Using duration of PTA as an indicator of severity of injury, this study found mild TBI accounted for 82%, moderate 9% and severe TBI a further 9%. Whilst these estimates are similar to Kraus's (1987) findings, Tate et al. (1998) identified a greater proportion of more severe injury.

Tate et al. (1998) investigated hospital separation data from 22 public hospitals in the North Coast region of New South Wales in the 1988 calendar year and again using duration of PTA as a measure of severity of injury, provide slightly different proportions. This study found mild TBI accounted for 62% of cases, moderate injury 20%, and severe TBI accounted for 14% of cases. Approximately 4% of subjects died after hospital admission. These proportions of people with more serious TBI were found to be much higher in this well designed study.

1.3.5 Sequelae and outcome

Outcome for survivors of TBI varies depending on a variety of factors such as location and extent of injury. In general, outcome has been related to

the severity of brain injury. Sequelae of mild, moderate and severe brain injury are differentiated in the literature (e.g., Bullinger, 2002; Ponsford et al., 1996; Ruff, 2005). These terms are used to describe the extent and persistence of changes in functioning following brain injury.

In the case of mild TBI, with PTA less than one hour, neurological deficits are usually temporary. The person may experience a range of temporary symptoms including headache, dizziness, sensitivity to noise and/or bright light, tinnitus, blurred or double vision, restlessness, insomnia, reduced speed of thinking, concentration and memory problems, fatigue, irritability, anxiety and depression (King, Crawford, Wenden, Moss, & Wade, 1995; Ponsford et al., 1996). These symptoms together are termed Post-concussion Syndrome (PCS) and generally resolve over a period of days or weeks (King, 1996). However several studies report 10% to 20% of people with mild TBI suffer ongoing cognitive deficits more than 90 days post-injury (Fortune & Wen, 1999; Ruff, 2005).

In studies examining longer-term outcome following mild TBI, areas of impairment most frequently noted were related to social adjustment such as participation in work or school, social contact, driving, and appropriate social interaction (Lezak & O'Brien, 1988; Ruff, 2005). Physical, cognitive, emotional and behavioural changes are more extensive and persistent in cases of moderate and severe TBI (e.g., Condeluci et al., 1992; Oddy, Coughlan, Tyerman, & Jenkins, 1985; Schretlen & Shapiro, 2003; Thomsen, 1994; Weddell, Oddy, & Jenkins, 1980). Examples of physical impairment can include hemiplegia, resulting in one sided weakness and loss of feeling, cranial nerve

deficits disrupting vision, hearing, smell and taste as well as balance and communication difficulties. Cognitive impairment can involve problems with attention, memory and learning as well as visuo-spatial ability and executive functioning including abstract thinking, speed of information processing, planning, problem-solving and self-monitoring (Schretlen & Shapiro, 2003). Affective disorders, particularly depression and increased irritability, are also a common consequence of TBI. Behavioural changes such as increased impulsivity, lack of personal awareness and self-centredness can strain interpersonal relationships. Problems in these areas are likely to lead to greater dependence on others for physical and practical support, and can lead to poor participation in pre-injury social activity (Ponsford et al., 1996).

These problems may be conceptualised as primary and secondary effects of TBI. Primary effects include problems in physical, cognitive, and emotional domains as a result of damage to brain tissue and functioning. Examples of such problems can include hemiplegia, memory and attention difficulties, and impulsivity, irritability or lability (Ponsford et al., 1996). Secondary problems occur as a direct result of these primary difficulties and may include withdrawal from social activity and social isolation, decreased self-esteem, self-medication with drugs of abuse, reactive depression and suicidality. Significant functional problems following TBI are likely to disrupt aspects of psychosocial functioning in areas of work, relationships, pursuit of leisure activities and independence (Kendall & Terry, 1996; Tate et al., 1989). Significant TBI can cause global disruption of aspects of personal and social functioning that reduces SQOL (Dijkers, 2004; Johnson & Miklos, 2002).

1.3.6 A model for understanding outcome following TBI

The complex array of outcome related factors presented above, and the important needs of people who are seeking to rebuild their lives in the community following TBI, is clarified within the framework of the World Health Organization's (WHO, 1999) generic model. In 1980, the WHO developed an international classification of impairments, disabilities, and handicaps (ICIDH), which was revised in 1997, changing the focus from *Disabilities* to *Activities* and *Handicaps* to *Participation* (WHO, 1999). Further development has seen the ratification in 2001 with the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). However, as this model remains under development (see Cameron, Tate & Leibbrandt, 2006) the ICIDH-2 model was chosen as the most useful framework relevant to TBI (WHO, 2001). Following are brief definitions of each of these constructs:

Impairments are losses or abnormalities of psychological, physiological, or anatomical structure or function.

Disabilities/Activities are the resulting changes in ability to perform functional activities. This includes any limitation, restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicaps/Participation are any disadvantage that limits or prevents fulfillment of a role that is considered normal. Handicaps are seen to be restrictions resulting from consequences of those disabilities in terms of normal role fulfillment in every day life, such as work, relationships and leisure activities (Brooks, 1992; Heinemann & Whiteneck, 1995).

In applying this model to outcomes following TBI, impairments are seen to lie in areas of sensory-motor function and in the cognitive processing of information. Disabilities/Activities can affect physical, cognitive and emotional domains (e.g., walking, hearing, remembering, and modulating emotions), and Handicaps/Participation can occur in many roles and aspects of daily life, including the critical areas of psychosocial functioning such as work, relationships, leisure and independence (Brooks, 1992; Tate & Broe, 1999).

Brown, Gordon, & Haddad (2000) explains that the ICIDH model follows a linear path, in that pathology produces impairment, which leads to disability. The interaction of impairment and disability with the environment in turn produce handicap, which can feed back to create secondary impairments, disabilities and handicaps. Examples of secondary problems include depression, problem-solving ability and access to transportation (Brown et al., 2000; Granger, Divan, & Fielder, 1995). Figure 1 depicts this process in diagrammatic form.

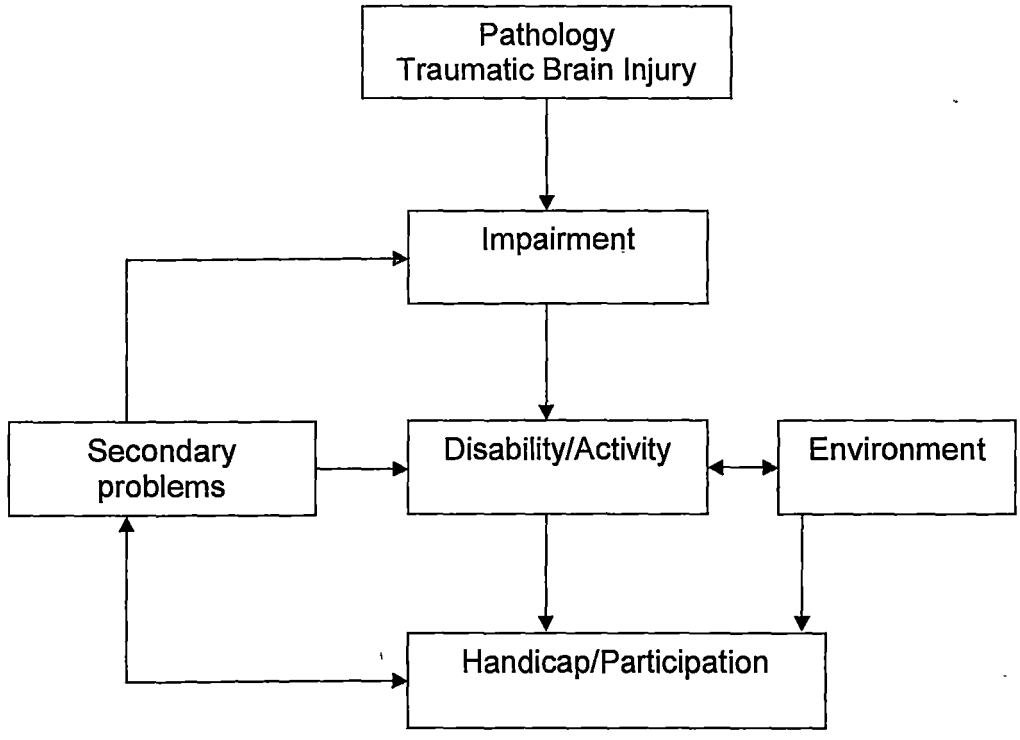


Figure 1.1. The ICIDH model as described by Brown et al. (2000)

Empirical research has provided support for the linear nature of the WHO ICIDH-model. In a study involving over 700 people with TBI, Heinemann & Whiteneck (1995) found evidence supporting a linear causal relationship from impairment to disability (ß = -.21, *r* = -.19) to handicap (ß = .32, *r* =.37). These authors also noted that handicap in social (*r* = -.32) and productive areas (*r* = -.31), (e.g., work, family, leisure and social life) were most strongly related to poorer life satisfaction, rather than impairment (*r* = -.01) or disability (*r* = -.13) variables. Based on this study, Heinemann & Whiteneck (1995) advanced the importance of handicap/participation as a key focus for rehabilitation efforts. This study has also reinforced findings of other studies that indicate variables in this

domain are the most salient predictors of SQOL outcome following TBI (Brown et al., 2000; Fuhrer, 1994; Granger et al., 1995).

1.4 Conceptualisation and definitions of quality of life

Ambiguity in definitions of QOL has created confusion in this area of research and hampered efforts to develop appropriate measures (Dijkers, 2004; Johnson & Miklos, 2002). However, a number of recent articles and an international consensus group have helped clarify conceptualisations and definitions within the context of recovery following TBI (e.g., Bullinger, 2002; Dijkers, 2004; Johnson & Miklos, 2002. Dijkers, 2004) differentiates QOL by objective or subjective views with three conceptions of QOL. In summary these include:

1.4.1 The aggregate approach

Social scientists and health economists have identified common metrics for cost and outcomes (e.g., Quality Adjusted Life Years or Disability-adjusted Life Years) for people with a range of disability including TBI. Using this approach to QOL, judgments about QOL are based on the values and standards of the society and the groups to which the judges belong, as well as judges' own life experiences. There is an ongoing debate about consensus issues in this area (Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001; Dijkers, 2004).

1.4.2 The objective approach

This approach to QOL determines a person's share of those characteristics that may be considered essential to "a good life" (e.g. work, friends, housing, health). Within this approach, judgments about a person's QOL are determined with a degree of objectivity, by an external observer. An example

of a measure that incorporates objective health related QOL (HRQOL) items is the SF-36 (Ware & Sherbourne, 1992; McHorney, Ware, & Raczek, 1993). As a measure of HRQOL, the SF-36 taps the extent to which a patient's usual or expected physical, emotional and social well-being are affected by a medical condition or its treatment (Johnson & Miklos, 2002). For example, items ask for ratings of limitations physical function such as walking one block, or climbing several flights of stairs. This measure has been used in TBI outcome research (e.g., Brown, Gordon, & Spielman, 2003; Emanuelson, Andersson, Holmvist, Bjorklund, & Stalhammar, 2003; Steadman-Pare, Colantonio, Ratcliff, Chase, & Lee, 2001). As the SF-36 taps physical and emotional functioning, HRQOL outcomes have been found to relate to symptoms of post-concussive syndrome (Emanuelson et al., 2003) and physical functioning (Steadman-Pare et al., 2001). In their review (Johnson & Miklos, 2002) cautions researchers that objective or HRQOL approaches to QOL conceptualisation and measurement do not adequately describe wider aspects of well-being, that range beyond medical or functionally related phenomena.

1.4.3 QOL as subjective well-being

This conceptualisation equates QOL with subjective well-being (SWB); that is, an individual's cognitive and emotional reactions to the balance of their achievements and expectations (Berger et al., 1999). Here, quality of life refers to a person's subjective evaluation of the degree to which his or her most important needs, goals, and wishes have been fulfilled. The smaller the perceived discrepancy between a person's aspirations and achievements, the greater his or her life satisfaction (Frisch, 1994).

Social scientists and economists most frequently use the aggregate approach to QOL conceptualisation. The objective and subjective approaches are utilised most commonly amongst researchers and clinicians in the TBI field. These latter approaches each have strengths and weaknesses. For example, the rigour of an objective approach to QOL assessment, where an external rater judges the subject's status based on a list of commonly desirable life variables has appeal. However, there has been debate about the relevance and importance of the variables listed in such checklists compared between subjects, and a number of other issues particularly associated with the development and administration of objective QOL measures (see Dijkers, 2004; Frisch, 1999). As such, consensus has not been reached on an appropriate objective QOL measure for use on the TBI field. Much of the recent literature argues that subjective measures of QOL provide a means to avoid problems with objective measurement and provides valuable insight into the personal relevance and meaning people assign to aspects of their well-being (e.g. Berger et al., 1999; Bullinger, 2002; Dijkers, 2004).

The subjective approach to QOL measurement asks the person to rate their own satisfaction with aspects of their life. This counters many of the problems associated with the more objective QOL approaches. Indeed, subjective quality of life (SQOL) has been described as the ultimate TBI outcome construct (Johnson & Miklos, 2002). Given the likelihood of TBI-related impairment impacting on psychosocial functioning, an individual's rating of SQOL can provide an understanding of an their perception of the fulfillment of their expectations, objectives, needs and desires across a key indicators

(Dijkers, 2004; Johnson & Miklos, 2002; Kalpakjian et al., 2004). This approach to QOL conceptualisation appeals strongly to those clinicians and researchers who desire an understanding of the "insiders' perspective" or personal reflection and rating of their own well-being or satisfaction with life (Berger et al., 1999).

Interestingly, a study sampling 8,550 people in China found a weak relationship between objective and subjective QOL, r = .24 (Li et al., 1998). Exceptions to this relationship were found amongst some younger people with high objective QOL status who rated low on SQOL measures, and older people who ranked lower on objective measures and reported higher SQOL. Other studies have noted similar differences in SQOL related to demographic variables (e.g., Seibert et al., 2002). In summary, Johnson & Miklos (2002) advanced an integrative definition of QOL, indicating "QOL may be taken as the totality of life experiences, objective and subjective, of the person and their appraisal of them" (p. S27). There is a great need for the development of normative references and validation of QOL measures within the TBI population.

Several studies as well as a recent TBI/QOL consensus groups have highlighted the value of the use of SQOL measures in measuring and understanding individual's outcomes following TBI (Brown et al., 2000; Bullinger, 2002; Dijkers, 2004; Johnson & Miklos, 2002; Neugebauer, Bouillon, Bullinger, & Wood-Dauphinee, 2002). Johnson & Miklos (2002) argue "leading researchers increasingly agree that QOL essentially involves appraisal of life or aspects of life by the person, using his or her own criteria." (p. S27). For example, recent research by Brown et al. (2000) examined models for predicting QOL outcome following TBI. These researchers found that the views of the individual with TBI

(n = 187) about how well their important needs were being met accounted for most of the variance in predicting their general satisfaction with life (r^2 = .15 to .47 for needs-based models). Whereas, objective measures such as the amount of supervision or physical assistance required, or number of cognitive complaints revealed little about how well individuals with TBI felt they were doing (r^2 = .13 to .24 for ICIDH models. In conclusion, Brown et al. (2000) asserted the personal, insider-assigned meaning attached to objective conditions was most important, as biological impairment, symptoms and functional limitations to QOL are mediated and modified by psychological, social and cultural factors.

1.5 Overview of SQOL outcomes following TBI

Very few outcome studies have specifically examined SQOL outcome following TBI. A recent review of quality of life after TBI has been conducted by Dijkers (2004), which examined the four studies that utilized either multidimensional and/or global SQOL measures (Brown & Vandergoot, 1998; Dawson, Levine, Schwartz, & Stuss, 2000; Kreuter, Sullivan, Dahloff, & Siosteen, 1998; Kolakowsky-Haner, Miner, & Kreutzer, 2001). In each study, people with TBI tended to report lower life satisfaction than their non-injured peers. However, Dijkers (2004) notes there was sizable variability within the samples and many subjects with TBI had life satisfaction similar to or even higher than the average non-TBI control participant. A small number of other studies were found to confirm poor SQOL outcome following TBI (Burleigh, Farber, & Gillard, 1998; Corrigan et al., 2001; Heinemann & Whiteneck, 1995; Hicken, Putzke, Novack, & others, 2002; Huebner, Johnson, Bennett, & Schneck, 2003; Kalpakjian et al., 2004; Mailhan, Azouvi, & Dazord, 2005).

These studies will be examined in detail later in the introductory chapters of this thesis.

1.6 SQOL and rehabilitation following TBI

In the 1980s, community re-entry programmes were established in North America and Europe for people with TBI who had completed hospital-based rehabilitation. Various models of community-based TBI rehabilitation have been operating in Australia since this time. Following on from acute treatment and in-patient rehabilitation, community-based rehabilitation programmes seek to complete a continuum of care for people with TBI and their carers.

Community-based rehabilitation is typically geared towards addressing issues of disability/activity and handicap/participation within the ICIDH model (Brown et al., 2000). Work at this level can encompass key elements of physical, psychological, cognitive and social functioning (Brooks, 1992; Burleigh et al., 1998; Jackson, 1994; Weddell et al., 1980). A stated objective of these types of service is the optimisation of quality of life of people with TBI and their families (Groswasser, 1994; MWBIRP, 1999).

It is widely recognised that peoples' subjective sense of well-being and quality of life are strongly related to their level of integration within their community. This is seen in their participation in purposeful work and leisure activities, and in the quality of their relationships with family and friends, their sense of purpose, meaning, or enjoyment as well as personal power and independence within their environment (Burleigh et al., 1998; Condeluci et al., 1992; O'Neill et al., 1998; Tate & Broe, 1999). Facilitation of individuals' progress with aspects of psychological adjustment and community reintegration

after TBI forms a major focus for community-based TBI rehabilitation. These rehabilitation efforts are closely aligned to optimising the activity and participation domains of the WHO ICIDH model.

The importance of the psychological process of adjustment to injury to the quality of life of people following TBI has received attention (e.g., Garske & Thomas, 1992; Karpman, Wolfe, & Vargo, 1985; Simpson, 1996). The complex and deeply personal process of adjustment has benefited from Simpson's (1996) theoretical framework for understanding the processes of psychological adjustment commonly observed in people with TBI. This model was developed to provide guidance for counsellors working in the area. It contains four tasks of adjustment, described briefly as follows:

1. ***Understanding:*** Acquiring an awareness of impairments and associated disabilities.
2. ***Re-integrating identity:*** The integration of old and new aspects (pre and post injury) of the person into a valued sense of self.
3. ***Acceptance:*** Processing the emotional impact of the injury, its sequelae and the ongoing process of recovery.
4. ***Restructuring:*** Modifying and adapting pre-injury skills and acquiring new skills in areas of relationships, employment and independent living.

In providing this conceptual framework of the tasks of adjustment to TBI, Simpson (1996) also provides guidance on relevant approaches to intervention, activity and support likely to be beneficial in facilitating adjustment. A strong heuristic link is observed between the application of the tasks of adjustment and the conceptualisation of SQOL. Dijkers (2004) explains SQOL is the cognitive

and emotional reaction to the balance of an individual's expectations and achievements.

Following TBI, individuals may perceive limitations in participation in valued social roles that reduce satisfaction across life domains. For example, an individual may not be able to return to their pre-injury occupation. However, on progressing with a process of adjustment to injury, this individual may come to accept this limitation, discover other vocational interests, skills, abilities and obtain other employment. When this occurs, the individual may be likely to rate greater satisfaction with their needs, goals and wishes in relation to their work than prior to commencing the adjustment process. Given the close conceptual relationship of Simpson's tasks of adjustment with SQOL, it is likely a measure of SQOL will serve as an indicator of adjustment to injury, although much research is needed in this area.

In summary, TBI can permanently impair functioning across key domains of everyday life. Limited physical, cognitive and emotional functioning can lead to reductions in participation in meaningful work and interpersonal relationships. This reduced participation is likely to lead to reduced SQOL. It is the role of community-based TBI rehabilitation to address these problems and optimize SQOL outcomes for survivors of TBI and their families.

As an indicator of functioning and outcome, SQOL has become an important construct in TBI rehabilitation service objectives. As such, it influences the operations of rehabilitation and community-support service delivery. Thus, it is important that the TBI field works with a clear conceptualization and understanding of this construct, and that the association of the construct of

SQOL is well understood in relation to other key outcome variables and constructs following TBI. It is also likely that a clear theoretical and empirical understanding of the predictors of SQOL outcome will serve to enhance delivery of rehabilitation services. However, to facilitate these objectives, an important initial step is the establishment and validation of acceptable measures of SQOL within the TBI context and refined understanding of aspects that predict SQOL following this type of injury.

Research has yet to establish a number of key specifics, including validation of appropriate SQOL measures within the TBI population, and comprehensive examination of longitudinal SQOL outcomes. Further studies are also required to establish the relationship of predictive variables to longitudinal SQOL outcomes from a comprehensive set of relevant domains.

1.7 The structure of this thesis

The focus of this thesis is to report research aimed at validating a measure of SQOL within a sample of people with TBI, and a systematic approach to identification of a predictive model of SQOL outcome following TBI. This thesis aims to represent a unique and important contribution to the TBI outcome research and rehabilitation fields.

With little previous research in this area, the process leading to the identification of a predictive model of SQOL outcome following TBI requires several stages, each making a unique contribution to the TBI/SQOL body of knowledge. These stages involve:

1. Identification and validation of an appropriate measure of SQOL within the TBI population.

2. Intermediate studies to establish the relationship of a comprehensive array of potential predictor variables with SQOL following TBI.
3. Application of regression analysis using these salient variables to provide a predictive model of SQOL following TBI.

The introductory chapters outline the TBI/SQOL outcome literature, and the considerations in choosing an appropriate measure of SQOL. This introductory review also provides a detailed examination of the variables shown to influence SQOL outcomes across five key domains commonly affected by TBI.

The research reported in this thesis first demonstrated the usefulness of the Quality of Life Inventory (QOLI, Frisch, 1994) in evaluating outcomes and the effectiveness of a structured TBI rehabilitation intervention. Then, as already described, the QOLI was validated within a sample of Australians with TBI in line with international TBI/SQOL consensus group recommendations (Bullinger, 2002; Neugebauer et al., 2002). These studies required a population-based, prospective approach to data collection, which was provided through the Neurotrauma Register of Tasmania. Intermediate studies examined the relationship of SQOL with a comprehensive array of predictor variables identified within the literature in five domain areas (e.g., Demographic/Injury, Physical, Cognitive, Social, and Emotional variables). The final study of this thesis identified a predictive model of SQOL.

In Chapter 2, considerations in selecting SQOL outcome measures are discussed. The Quality of Life Inventory (QOLI, Frisch, 1994) was identified as an appropriate SQOL outcome measure within the TBI context. A detailed

description of this measure is provided including theoretical grounding, psychometric properties and distribution of the US-based standardization sample.

A detailed review of outcome research following TBI across five key domains of affecting QOL is provided in Chapter 3. Variables shown to relate to SQOL following TBI are identified together with preliminary discussion of appropriate measures. The chapter concludes with the rationale for further studies within this thesis.

Study 1 is presented in Chapter 4. This study demonstrated the utility of the Quality of Life Inventory (QOLI, Frisch, 1994) in evaluating psychosocial adjustment outcomes in relation to two pilot TBI rehabilitation programmes, and raised questions about the application of the normative distribution of the US-based standardization study within the Australian TBI context.

The normative distribution of a large sample of Australians with TBI is compared with the generic, US-based QOLI normative distribution in Chapter 5, in Study 2. Pre-injury estimates of a large sample of Tasmanians with TBI are used to provide the comparative normative distribution. The factor structure of the QOLI for this Australian sample is also identified in Study 2, giving insight into the structure of SQOL following TBI. Following this validation of the QOLI within an Australian TBI sample, Study 3 details the longitudinal outcome of a population-based sample of Tasmanians with TBI using the QOLI at time points to twelve months following injury. Study 3 is provided in Chapter 6.

Chapter 7 introduces the fourth study, which examines the salience of the relationship of predictors of SQOL identified in previously published research.

Study 4 is divided into five correlational sub-studies. In each of these sub-studies, the outcomes and relative strength of relationships of each predictor variable is examined in relation to SQOL as measured by the QOLI. An explanation of these domains and variables of interest is provided in Chapter 3. A separate chapter is given for correlational studies of variables of interest and SQOL across each domain, as follows:

- Chapter 8 reports Study 4.1 - Demographic and clinical domain
- Chapter 9 reports Study 4.2 - Physical domain
- Chapter 10 reports Study 4.3 - Pychological domain
- Chapter 11 reports Study 4.4 - Social domain
- Chapter 12 reports Study 4.5 - Cognitive domain

The results of Study 4 are summarised and integrated in Chapter 13. Study 5 establishes predictive models of SQOL outcome in Chapter 14. In this final study, the predictors seen to relate to SQOL from the five domains examined in Study 4 were entered into regression equations to produce these predictive models. Chapter 15 provides a discussion of the application of these findings and limitations of the methodologies employed, and suggests future directions for SQOL/TBI research.

CHAPTER 2

MEASUREMENT OF SUBJECTIVE QUALITY OF LIFE FOLLOWING TRAUMATIC BRAIN INJURY

This chapter presents a detailed examination of considerations supporting selection of an appropriate measure of subjective quality of life (SQOL) for use within the TBI population. The literature shows a number of different measures have been used for this purpose. However, following the considerations outlined in this chapter, the Quality of Life Inventory (Frisch, 1994) was identified as meeting the identified requirements.

Several studies have examined the normative and psychometric qualities of the QOLI within clinical and disabled groups, such as people with depression and social anxiety (e.g., Eng, Coles, Heimberg, & Safren, 2005; Frisch, 1999). Only one study was found that utilised this measure to examine SQOL outcomes following TBI (Kalpakjian et al., 2004). Details of this study are presented in this chapter. As only one study was identified having used the QOLI within a TBI sample, studies utilising the QOLI with other clinical groups are reviewed. This chapter concludes with a discussion of the importance of further research to validate the QOLI within a TBI sample.

2.1 Considerations in the selection of SQOL measures

A recent consensus group reviewed the status of TBI/SQOL outcome research and the available SQOL measures (Bullinger, 2002). This group concluded they were not able to recommend any specific measures of SQOL for use within the TBI context. The reason given was that too little empirical research was available elucidating the strengths and limitations of the measures

examined by the group. Rather, the TBI/QOL consensus group recommended further investigation of generic SQOL instruments and the predictors of SQOL within TBI populations (Bullinger, 2002).

Guidance on a number of considerations in selecting SQOL measures has been gleaned from the relevant literature. These points include the application of dimensionality in questionnaire design, importance weighting across SQOL domains, the importance of psychometric integrity and a concise and self-explanatory design, as well as the need for validation of generic measures within the TBI population (e.g., Berger et al., 1999; Dijkers, 2004; Johnson & Miklos, 2002). In the following subsections, the literature on each of these topics is reviewed to determine the best features and facilities in selecting a SQOL measure for use in TBI outcome research.

2.1.1 Dimensionality of SQOL measures

Two main approaches to questionnaire design have been the use of global scales and in contrast, the creation of multidimensional scales of SQOL. Global approaches to measuring SQOL generally ask an individual to give an overall rating of their satisfaction with their everyday life (e.g. Brown & Vandergoot, 1998; Steadman-Pare et al., 2001). This may involve the respondent indicating their perception of their quality of life on a likert scale using numbers or single-word descriptions. For example respondents may rate their SQOL on a scale of zero to 10 where 10 is labelled with a happy face and zero a sad face, or where zero is labelled "Terrible" and 10 "Delighted" (e.g. Andrews & Whithey, 1976).

There have been several points presented in favour of the global approach to SQOL measurement. These have included a presumed increase in compliance with a single item response over a multi-question scale. Also, the use of a numbered likert scale has been thought to facilitate an "internal calibration" where respondents choose six on a scale of zero to 10 to indicate 60% satisfaction with their SQOL (Steadman-Pare et al., 2001). In the recent literature however, arguments have been raised against the global approach to SQOL measurement in the TBI population. Some difficulties highlighted with global approaches to SQOL assessment include ambiguity of the definition of QOL taken by both researchers and respondents, and the use of brief questions and subsequent risk of researchers receiving casual answers from respondents (Dijkers, 2004).

With these arguments against use of global scales, another approach to SQOL questionnaire design has been the use of multidimensional scales. Stemming from conceptual and definitional bases, the multidimensional approach to SQOL measurement seeks to assess life experience broadly, across a number of defined factors such as work, relationships, finances, leisure pursuits and living conditions (Johnson & Miklos, 2002). Recent research recommends the use of multidimensional measures with TBI samples, as this may work to clarify meanings of SQOL domains with the respondent and serve to optimise reliability of self-reporting (e.g., Bullinger, 2002; Johnson & Miklos, 2002). The issue of reliability of self-reporting amongst TBI respondents is discussed later in this chapter.

2.1.2 Importance weighting of domains

A further development reflected in SQOL measures is that of importance weighting across QOL domains. When incorporated into a multidimensional SQOL measure, importance weighting allows respondents to indicate the relative importance of each domain to their overall well-being. Ferrans and Powers (1985) explain that because people differ with regard to which domains are most important to them, simple addition of satisfaction ratings across domain areas yields an inaccurate representation of SQOL. Additionally, Cummins (1995) asserts that if a respondent regards a domain of an SQOL scale to be irrelevant to their personal situation, their satisfaction or dissatisfaction with this domain is irrelevant as it contributes little to the individual's life. Conversely, satisfaction with a life domain that a person believes contributes more strongly to their well-being will be of much greater significance, and should be taken into greater account. Indeed, Brown et al. (2000) explain that importance ratings "allow one to hear more of the insider's voice than when assuming equivalent importance of need domains..." (p. 17).

In summary, several TBI/SQOL reviews recommend the use of importance weighting in multidimensional SQOL measures, as it provides scope to incorporate differences in respondents' values across the domains of their lives (e.g., Bullinger, 2002; Dijkers, 2004; Kalpakjian et al., 2004). However, other SQOL researchers have argued against the inclusion of importance-weighting (e.g., Cummins, 2005; Trauer & Mackinnon, 2001).

Trauer and Mackinnon (2001) asserted that importance-weighting is undesirable and unnecessary. These authors raise a number of objections to the use of importance-weighting, as they point out the following:

- Given the extensive development of SQOL scales, the domains of SQOL measures are universally relevant. It was suggested that satisfaction ratings already reflect a personal appraisal of the importance of the domain to the respondent.
- Interpretation of the multiplicative composite (i.e. Importance x Satisfaction ratings) may be misleading, such as when a high Importance score is multiplied by a low Satisfaction score and vice versa yielding similar scores.
- A number of authors have noted that inclusion of importance ratings produced little or no detectable increase in the power of satisfaction ratings to correlate with criteria variables (Walters & Roach, 1971), to predict global well-being (Campbell, Converse, & Rodgers, 1976), nor discriminate between high and low total SQOL (Cummins, McCabe, Romeo, & Gullone, 1994).
- Correlations between importance-weighted and unweighted satisfaction scores are reportedly very high. For example, in a study of 139 people on the ComQoL (Cummins et al., 1994), Trauer and Mackinnon (2001) found correlations of .97 between the means of the satisfaction scores and importance–weighted satisfaction scores. Likewise, Likert (1932) found a

correlation of .99 between unweighted scores with scores obtained by an elaborate method of weighting each item.

In summary, Trauer and Mackinnon (2001) argue importance-weighting adds little to satisfaction ratings in the measurement of SQOL. Recent research by Wu and Yao (2006) sought to empirically test whether importance-weighted satisfaction scores were superior to the un-weighted scores in predicting a global life satisfaction measure, and examined the moderating effect of item importance on relationships between item satisfaction and overall life satisfaction, concluding importance weighting was unnecessary. However, the study relied on a sample of 130 undergraduate students, which was not representative of the general population, and relied on a global measure of QOL as the dependent variable upon which to test importance weightings. These serious limitations undermine the results and application of this study.

Whilst explaining their opposition to importance-weighting in statistical terms Trauer and Mackinnon (2001) provide no empirical evidence to support their position and concede that there may be compelling practical reasons to include importance weighting. Given the lack of evidence against importance-weighting and the calls in the recent SQOL/TBI literature to include importance-weighting in any prospective SQOL measure, it is likely this question requires further research within the TBI population.

2.1.3 Psychometric integrity

SQOL measures require thorough research to establish their validity, reliability and normative characteristics within the intended population. Whilst each of these concepts are multifaceted, a basic approach to ensuring

psychometric integrity includes research to ensure the measure is reliably measuring its intended construct (SQOL) as conceptualised and elucidated, and not some other confounding construct. It is also useful to have reference to normative data for the measure, to facilitate comparison of responses of individuals and groups within specific clinical population distributions. This facility is important when demonstrating outcomes in general, over time and in relation to rehabilitation interventions (Kaplan & Saccuzzo, 1997).

2.1.4 Concise and self-explanatory survey design

A basic facility of any survey is its ability to pose questions of respondents that are easily understood, and which facilitate a useful response. As people with TBI may be likely to suffer cognitive impairment reducing their attention and memory functioning, any measure designed for self-reporting purposes within this population will do well to include concise explanations of concepts and instructions that facilitate an appropriate response.

Indeed, given the possibility of disruption to cognitive and affective functioning, a frequently discussed limitation of the subjective approach to TBI outcomes research is the issue of reliability of self-report measures within the TBI population. Some researchers have urged that people with moderate or severe TBI lack insight, memory or communicative skills to provide useful or complete responses on these types of questionnaires. As such, some studies have relied on the reports given by TBI patients' relatives or carers (e.g. Goldstein et al., 1999). Other researchers have conducted large-scale investigations for possible discrepancies between self-reports of people with TBI and their proxies, and found little differences (e.g. Cusick, Gerhart, & Mellick,

2000; Deloche, Dellatollas, & Christensen, 2000; Teasdale et al., 1997). A multidisciplinary TBI consensus conference held in 1999 concluded that the patient's self report had to be taken as the primary QOL measure even if his or her cognitive status was impaired (Neugebauer et al., 2002).

It appears the issue of whether people with TBI are reliable reporters has not yet been adequately resolved (Dijkers, 2004). However, given the personal nature of interpreting and appraising aspects of life satisfaction, it seems likely that people with TBI, rather than proxies will provide the best responses to SQOL measures. An ideal SQOL measure for use within the TBI population would include a concise, concrete explanation of domains, with instructions that lead the respondent to make a clearly interpretable indication on each item.

2.1.5 Practical interpretation

Multidimensional SQOL measures may be used differently within TBI outcome research and rehabilitation contexts. In outcome research, a total or summary score may be of primary importance. Whereas, in the rehabilitation context domain scores may be the focus for a clinician who interprets variations between domains, and may use domain responses to assess the respondent's needs, and resources as a means of remedying psychosocial problems (Frisch, 1999). As such, an asset of an SQOL measure within the TBI context would include provision of domain and a total average domain scores. A measure of SQOL with both these scoring features can establish an individual's level of functioning and have useful applications in individual therapy, programme evaluation and outcome research.

In summary, the selection of an SQOL measure requires an importance weighted, multidimensional measure with clear and simple definitions of its domains, and of the domain importance rating system. Practically, an appropriate measure requires minimal time to complete, and a focussed format to engage respondents and optimise reliability of self-reporting. Such a measure would be valuable in monitoring patients' progress within a rehabilitation context and for use in outcome research within the TBI population.

2.2 Introduction to the Quality of Life Inventory (Frisch, 1994)

The Quality of Life Inventory (Frisch, 1994) was identified as meeting the requirements of an SQOL measure discussed above. The QOLI is an importance-weighted, multi-dimensional measure of SQOL that taps life satisfaction (Frisch, 2004). It was developed as a measure of an individual's SQOL within medical and psychological contexts (Frisch, 1994). An example of the QOLI is attached in Appendix A (see Chapter 2 on the Appendix CD).

The QOLI has undergone extensive normative and psychometric investigations within a stratified sample of non-disabled North Americans (Frisch, 1994) and is considered to have excellent psychometric characteristics (Frisch, 2004). In addition to this normative research, several studies have examined the psychometric properties of the QOLI within clinical and disabled groups, such as people with depression, social anxiety, and chronic back pain (Claiborne, Krause, Heilman, & Leung, 1999; Eng et al., 2005; Frisch, 1999). Only one study was found that utilised this measure to examine SQOL outcomes following TBI (Kalpakjian et al., 2004). Details of these studies are presented later in this chapter.

2.2.1 Theoretical grounding and purpose of the QOLI

The QOLI was designed for broad use in mental health and other rehabilitation outcomes measurement. It has been used to fulfill roles as a measure of both clinical and research outcomes. This measure has been shown to be sensitive and useful in a range of therapeutic applications including rehabilitation outcomes evaluation (Frisch et al., 1992; Frisch, 1999).

The QOLI is grounded in Frisch's empirically validated quality of life theory (Frisch, 1994; Frisch, 1998). Figure 1 depicts Frisch's (1994) Quality of Life model of life satisfaction and subjective well-being.

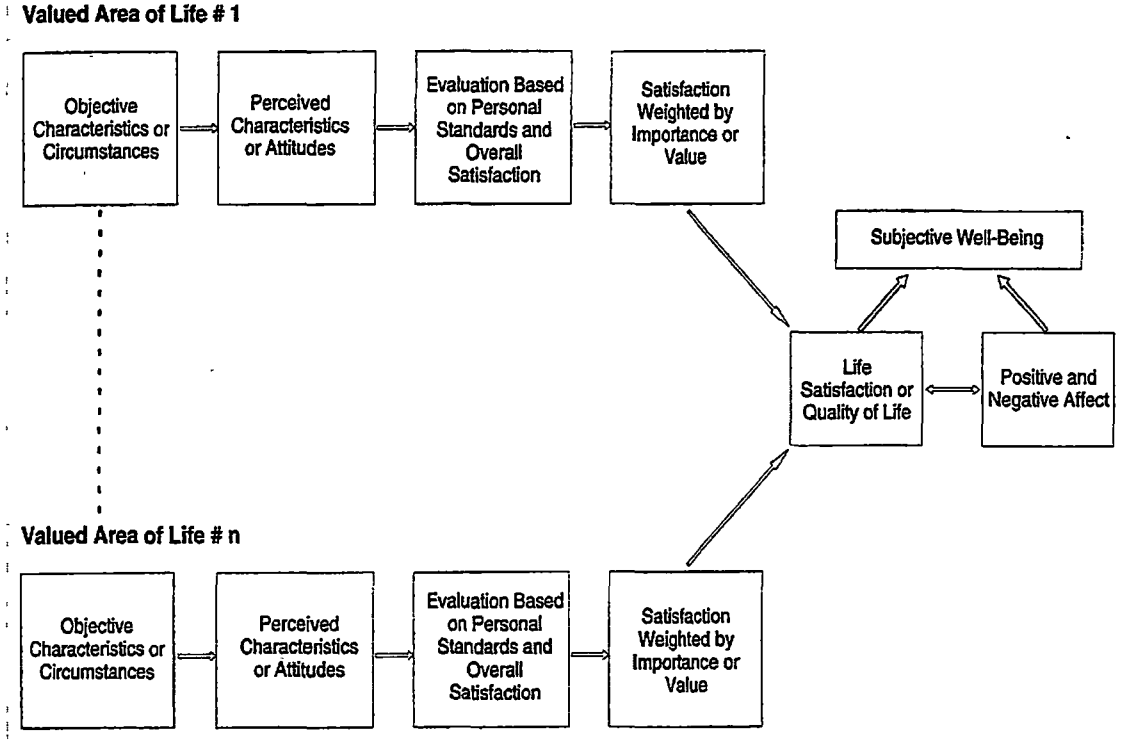


Figure 2.1. Quality of Life model of life satisfaction and subjective well-being *(Frisch, 1994)*

In this model, quality of life is equated with life satisfaction and refers to a person's subjective evaluation of the degree to which their needs, goals and

wishes have been fulfilled. Life satisfaction is defined as the perceived gap between a person's aspirations and achievements. Frisch (1994) explains the smaller the gap between a person's aspirations and achievements, the greater his or her life satisfaction.

The model is said to be linear and additive. It assumes a person's overall life satisfaction consists largely of the sum of satisfaction ratings across particular areas of life that are valued and therefore deemed important. Frisch et al. (1992) assert that the inventory's scoring scheme reflects the assumption that a person's overall life satisfaction is a composite of the satisfaction in particular areas of life weighted by their relative importance to the individual. Frisch (1994) explains a person's satisfaction in a particular area of life is made up of four components:

1. Objective characteristics or circumstances of an area
2. How the person perceives and interprets an area
3. The person's evaluation of fulfillment in an area, based on application of standards of fulfillment or achievement
4. The value or importance the person places on an area regarding his or her overall happiness or well-being.

2.2.2 Domains of the QOLI

The QOLI has sixteen domains. A concise definition for each domain is provided on survey sheets provided to respondents. The domains of the QOLI and their definitions are provided below in Table 2.1.

Table 2.1

QOLI domains and definitions

QOLI Domain	Domain Definition
HEALTH	is being physically fit, not sick and without pain or disability.
SELF ESTEEM	means liking and respecting yourself in light of your strengths and weaknesses, successes and failures and ability to handle problems.
GOALS-AND-VALUES	are your beliefs about what matters most in life and how you should live, both now and in the future. This includes your goals in life, what you think is right or wrong, and the purpose or meaning of life as you see it.
MONEY	is made up of three things. It is the money you earn, the things you own (like a car or furniture), and believing that you will have the money and things that you need in the future.
WORK	means your career or how you spend most of your time. You may work at a job, at home taking care of your family, or at school as a student. WORK includes your duties on the job, the money you earn (if any), and the people you work with. (If you are unemployed, retired, or can't work, you can still answer these questions).

Table 2.1 (continued)

PLAY	is what you do in your free time to relax, have fun, or improve yourself. This could include watching movies, visiting friends, or pursuing a hobby like sports or gardening.
LEARNING	means gaining new skills or information about things that interest you. LEARNING can come from reading books or taking classes on subjects like history, car repair, or using a computer.
CREATIVITY	is using your imagination to come up with new and clever ways to solve everyday problems or to pursue a hobby like painting, photography, or needlework. This can include decorating your home, playing the guitar, or finding a new way to solve a problem at work.
HELPING	means helping others in need or helping to make your community a better place to live. HELPING can be done on your own or in a group like a church, a neighbourhood association, or a political party. HELPING can include doing volunteer work at a school or giving money to a good cause. HELPING means helping people who are not your friends or relatives.
LOVE	is a very close romantic relationship with another person. LOVE usually includes sexual feelings and feeling loved, cared for, and understood. (If you do not have a LOVE relationship, you can still answer these questions.)

Table 2.1 (continued)

FRIENDS	are people (not relatives) you know well and care about who have interests and opinions like yours. FRIENDS have fun together, talk about personal problems, and help each other out. (If you have no FRIENDS, you can still answer these questions.)
CHILDREN	means how you get along with your child (or children). Think of how you get along as you care for, visit, or play with your child. (If you do not have CHILDREN, you can still answer these questions.)
RELATIVES	means how you get along with your parents, grandparents, brothers, sisters, aunts, uncles and in-laws. Think about how you get along when you are doing things together like visiting, talking on the telephone, or helping each other out.
HOME	is where you live. It is your house or apartment and the yard around it. Think about how nice it looks, how big it is, and your rent or house payment.
NEIGHBOURHOOD	is the area around your home. Think about how nice it looks, the amount of crime in the area, and how well you like the people.

Table 2.1 (continued)

COMMUNITY	is the whole city, town, or rural area where you live (it is not just your neighborhood). COMMUNITY includes how nice the area looks, the amount of crime, and how well you like the people. It also includes places to go for fun like parks, concerts, sporting events, and restaurants. You may also consider the cost of things you need to buy, the availability of jobs, the government, schools, taxes and pollution.

2.2.3 QOLI scoring system

Respondents complete importance ratings and satisfaction ratings for each of the 16 domains, rating 32 items in total. The importance weighting facility allows respondents to indicate the relative value they place on each domain, by rating importance on a three-point scale (Not important = 0, Important = 1, Extremely Important = 2). Respondents rate their satisfaction on each domain on a six-point scale (from Very Dissatisfied = -3 to Very Satisfied = +3) for each domain. Multiplication of importance scores (0, 1 or 2) by satisfaction scores (-3 to +3) provides importance weighted satisfaction scores for each domain. A total QOLI score is obtained by averaging domain scores. Total scores may be converted to T-scores and percentile rankings when compared with the QOLI normative sample (Frisch, 1994). Table 2.2 provides the QOLI ranges based on the standardisation sample presented by Frisch (1994).

Table 2.2

SQOL Classifications Based on Raw scores, T-Scores and Percentiles

Overall QOL Classification	Raw Score Range	T- Score Range	Percentile Range
High	3.6 to 6.0	58 to 77	81^{st} to 99^{th}
Average	1.6 to 3.5	43 to 57	21^{st} to 80^{th}
Low	0.9 to 1.5	37 to 42	11^{th} to 20^{th}
Very Low	-6.0 to 0.8	0 to 36	1^{st} to 10^{th}

2.2.4 Validity and Reliability

The QOLI manual provides results of validity and reliability studies (Frisch, 1994). The reliability and validity of the QOLI have been reported to be very good. The QOLI was shown to be positively and significantly correlated with the Satisfaction With Life Scale (Diener, Emmons, Larsen, & Griffith, 1985) (r =.56, p<.001), and Quality of Life Index (Ferrans & Powers, 1985) (r =.75, p<.001). Test-retest reliability coefficients were reported at 0.73 (p<.001) and internal consistency for the sum of the weighted satisfaction ratings, α = 0.79.

2.2.5 Normative distribution of the QOLI

Results of a generic, US-based standardization study (n= 798) were reported in the QOLI manual (Frisch, 1994), which noted some biases in the standardization sample. These included a majority of respondents being female (approximately 65%). A smaller over-representation of Hispanic and Black respondents was also noted. Frisch (1994) reported a 2% over-representation of Black and 4% over-representation of Hispanic respondents compared with the US Census of 1992. The largest bias was on years of education, where the greatest proportion of respondents had at least four years of post-high school education (mean years of education = 15.6, *SD* = 2.9, Range = 8 to 29 years). Although no indication is available as to the population norm on this demographic variable, the distribution of the normative sample appeared high.

Frisch (1994) also reported results of analyses examining differences within the standardization sample, on the QOLI, across various demographic variables including ethnic origin, gender, age and education level. In summary, two-way analysis of variance (ANOVA) found no significant differences for gender by race and ethnic group, indicating that males and females across race and ethnic groups scored similarly on the QOLI. Some significant differences were found between race and ethic groups, with Hispanic people rated higher SQOL than Black and White respondents. Weak positive correlations were noted for age (r = .04, p<.05, n =788) and years of education (r =.10, p<.05, n =763). The normative distribution of the standardization sample is presented in Table 2.3 below.

Table 2.3

Comparison of Normative Statistics for the QOLI in Frisch (1994)

Statistic	N = 798
Mean	2.60
Standard Deviation	1.30
75th percentile	5.70
25th percentile	1.80
Minimum	-3.88*
Maximum	5.88*

* Taken from clinical samples reported in (Frisch et al., 1992).

2.3 Research utilising the QOLI within TBI populations

Only one published study was found in which the QOLI was used in outcome research within a TBI sample (Kalpakjian et al., 2004). In a preliminary attempt to provide distribution and psychometric information relevant to the TBI population, (Kalpakjian et al., 2004) utilized a cross sectional design with 50 adult participants, who had sustained severe TBI (Mean GCS = 8.74), and were more than five years post injury (*M* = 5.68, *SD* = 3.07). It is noted this study was limited by sample size, and the design did not specify outcomes for participants with a range of severity of injury. In addition, the factor structure of the QOLI was not investigated and as such, remains unknown within a TBI sample.

With this modest sized sample, Kalpakjian et al. (2004) reported a mean QOLI score in the Low Average range (T-score mean = 43.08, *SD* = 17.24), which was generally consistent with previous TBI/SQOL research using other measures (e.g. Brown & Vandergoot, 1998; Hicken et al., 2002; Webb et al., 1995). The QOLI distribution of this TBI sample appeared much lower than that of the non-disabled standardisation sample. This adds weight to calls for validation of generic measures such as the QOLI within the TBI population (Bullinger, 2002).

2.3.1 Factor analyses of QOLI domains within other clinical populations

As only one published study was identified utilising the QOLI within a TBI sample, and this did not report a factor analysis of the QOLI domains, a review was undertaken to identify studies reporting the factor structure of the

QOLI in other clinical populations. Three published studies were found in which the structure of the QOLI was investigated within other clinical populations. These are presented separately as follows.

Eng et al. (2005) investigated the structure of the QOLI within a sample of 138 people suffering social anxiety. This study aimed to identify domains of life satisfaction in social anxiety disorder and differential changes in these domains following cognitive-behavioural group therapy. An exploratory principal components factor analysis of the items of the QOLI yielded four domains of life satisfaction accounting for 61% of the overall variance. A summary of the four factors and the domains that loaded onto these is provided below in Table 2.4. Interestingly, the results of this study showed people with social anxiety disorder were not characterised by global dissatisfaction but were particularly dissatisfied with the quality of their Achievement and Social Functioning.

A second study by Claiborne et al. (1999) examined SQOL outcome amongst 253 people who experienced chronic back pain. This analysis identified five factors, which were similar to those reported by Eng et al. (2005). Further details of this exploratory factor analysis are provided in Table 2.4. However, few details of the factor analysis were reported and the variance explained by factors was not reported. This study appeared to report an exploratory analysis, and appropriate confirmatory analysis was lacking.

A third, most recent study by O'Cleirigh and Safren (2006) examined factors of life satisfaction for people who were HIV positive. This was conducted as part of a clinical trial that examined adherence to treatment.

The sample was mostly male (83%), and all participants were considered to be at risk of not adhering to antiretroviral treatment. An exploratory factor analysis of 152 respondents with HIV found four factors with Eigen values greater than one, and the solution explained 50% of the variance. Items were retained if their factor loadings were .30 or greater. The factor structure of this clinical sample is provided in Table 2.4 below.

In summary, the results of this exploratory research with cohorts from other clinical backgrounds establishes a need for structural analysis of the QOLI within specific clinical populations and suggests there may be particular factors that are more relevant to the traumatic brain injury (TBI) population. Although factors appeared similar, subtle differences suggest people with different clinical backgrounds may rate greater dissatisfaction on specific combinations of the QOLI domains. This may have implications for focussing therapeutic interventions specific to TBI.

Table 2.4

QOLI factors and domains derived from other clinical populations.

Chronic back pain (EFA, n=253) (Claiborne et al., 1999)	Social anxiety (EFA, n=138) (Eng et al., 2005)	HIV infection (EFA, n=152) (O'Cleirigh & Safren, 2006)
1. **Family support:** Love, Friends, Children, Relatives.	1. **Social functioning:** Play, Love, Helping, Friends, Relatives.	1. **Interpersonal relationships:** Relatives, Children, Love, Friends, Helping.
2. **Environment:** Home, Neighbourhood, Community.	2. **Surroundings:** Neighbourhood, Community.	2. **Environment:** Community, Neighbourhood, Home.
3. **Personal growth:** Learning, Creativity, Helping.	3. **Personal growth:** Goals & values, Learning, Creativity	3. **Self-expression:** Learning, Creativity, Play.
4. **Accomplishment:** Goals & values, Money, Work, and Play.	4. **Achievement:** Self-esteem, Money, Work, Home.	4. **Achievement:** Self-esteem, Health, Money, Goals & values, Work.
5. **Health:** Health, Self-esteem.		

2.4 The need for validation of the QOLI within the TBI population

In summary, this chapter has presented considerations in selecting a measure of SQOL for use within the TBI population and examined the QOLI as a measure that meets these criteria. In contrast with the inadequacies of other approaches to SQOL measurement, such as using a global rating of SQOL, or the use of health-impairment focussed questionnaires as measures of general quality of life, the QOLI appears to cover a broad range of domains and to include many of the key aspects affecting QOL following TBI. The QOLI meets the requirements for an importance weighted multi-dimensional measure of SQOL and provides a valuable opportunity to clarify the structure of general SQOL for people with TBI (Dijkers, 2004; Kalpakjian et al., 2004). However, the QOLI is a generic measure, and to date, published research using it within the TBI population has been very limited.

When considering generic measures of SQOL for application in the TBI population, the current consensus suggests there is a need for the validation of such instruments within this population (Bullinger, 2002; Kalpakjian et al., 2004; NIH, 1999). In considering measures that have not been specifically validated within a particular population researchers and clinicians "...can not make supportable decisions about the selection of instruments and interpretation of data when information is lacking about the distribution of scores and psychometric characteristics in a TBI sample, compared with normative samples" (Kalpakjian et al., 2004, p. 256). As such, the QOLI requires validation within the TBI population (Berger et al., 1999; Dijkers, 2004). The apparent limitations with the QOLI standardisation sample and skewed distribution of the

only published TBI outcome study utilising the QOLI suggest it is important to compare normative distributions of the QOLI standardisation sample with a large cohort of people with TBI. This is in line with calls from recent TBI research consensus groups (e.g., Bullinger, 2002; NIH, 1999). Based on the subtle differences observed in factor structure of the QOLI between two clinical populations (e.g. Claiborne et al., 1999 and Eng et al., 2005), there is also a need to investigate and confirm the factor structure of the QOLI within the TBI population, before examining longitudinal outcomes and proceeding with the process of identifying predictive models of SQOL outcome following TBI.

The next chapter reviews TBI/SQOL outcome research and reviews studies that have attempted to identify predictive models of outcome. The chapter is structured to provide details of the salient variables found to relate to SQOL outcome following TBI across broad domains of functioning. Within this discussion of predictor variables, a description is also provided of measures of these variables.

CHAPTER 3

PREDICTORS OF SUBJECTIVE QUALITY OF LIFE FOLLOWING TRAUMATIC BRAIN INJURY

This chapter completes the introduction to this thesis by summarising the results of preliminary modelling research of SQOL outcome and other correlational studies. Very few published studies have attempted to identify a predictive model of SQOL outcome. There has been much more research concentrating on identifying outcome following TBI and correlates of outcome. In recent years several review articles have helped to organise this information.

In reviewing the TBI/SQOL research conducted to date, it is clear many of these studies suffer from a range of methodological problems. These limitations have included use of global measures of SQOL, which risks poor reliability of responses (as already discussed in Chapter 2), and small sample sizes, leading to difficulties in statistical prediction of SQOL outcome. Indeed, only a few TBI/SQOL outcome studies have utilised sample sizes large enough to adequately perform factor and regression analysis procedures (e.g., Brown & Vandergoot, 1998, n = 430 TBI participants; Steadman-Pare et al., 2001, n = 275 TBI participants; Vanderploeg, Curtiss, Duchnick, & Luis, 2003, n = 626 mild TBI participants). These studies were performed retrospectively on databases accrued over long periods of time. The large numbers of participants in these few studies are quite unusual within the literature.

Most studies have utilised smaller samples, to indicate relationships between a range of variables and SQOL measures, (e.g. Huebner et al., 2003, n = 25 TBI participants; Johansson and Bernspang, 2003, n = 36 TBI participants;

Kalpakjian et al., 2004, *n* = 50 TBI participants; Koskinen, 1998, *n* = 15 severe TBI participants; Mailhan et al., 2005, *n* =75 mild TBI participants). However, research that aims to identify the salience of variables in predicting SQOL outcome requires an adequately large sample size to sustain the use of appropriate statistical procedures.

A further problem highlighted in studies attempting to identify predictive models of SQOL is the narrow focus often taken by researchers when identifying predictor variables. Recent reviews and a consensus conferences have called on TBI/SQOL researchers to use multidimensional SQOL measures and predictor variables that tap broad domains of functioning following TBI (e.g., Brown & Vandergoot, 1998; Berger et al., 1999; Bullinger, 2002; Johnson & Miklos, 2002).

In addressing these deficiencies, the following review of critical constructs and variables related to SQOL is undertaken within the context of five broad domains. These include demographic and clinical variables, physical and cognitive functioning, psychological factors such as affect, and aspects of social functioning. As there have been few studies examining SQOL outcome, studies examining aligned variables including life satisfaction, and aspects of psychosocial functioning are also reviewed. The chapter concludes with a summary and outline of directions for research reported in this thesis.

3.1 Predictive models of SQOL following TBI

There have been some preliminary attempts to provide predictive models of SQOL outcome following TBI. These studies have investigated the role of particular aspects following TBI, such as indicators of severity of injury, mood,

motor independence, or community integration on SQOL (e.g., Brown et al., 2000; Corrigan et al., 2001; Dawson et al., 2000; Novak, Bush, Meythaler, & Canupp, 2001; Warren et al., 1996; Webb et al., 1995). Whilst these studies have not taken a comprehensive approach to identifying variables across salient domains of functioning, their findings have implications for selecting variables with predictive power and are discussed as follows.

A study by Brown et al. (2000) found subjective indicators of psychosocial functioning predicted more variance on both global and multidimensional measures of life satisfaction than objective measures of impairment and disability. This well designed study utilised a large sample of people with TBI (n = 430) and compared the efficacy of models based on the WHO ICIDH conceptualisation with needs-based models in predicting SQOL outcome. Results reinforced both the need to use importance-weighted, multi-dimensional SQOL measures, and selection of predictive variables that tap psychosocial functioning or the ICIDH Handicap/Participation domain.

Corrigan et al. (2001) examined correlates of life satisfaction following TBI within a prospective sample of 218 participants, studied one and two years after injury. Stepwise multiple regression identified models explaining 14% of variance at Year 1 and 30% of variance at Year 2. Key correlates were not having a pre-injury history of substance abuse (ß = -4.74, p< .000 at Year 1), having gainful employment (ß = 2.58, p = .03 at Year 1 and 3.82, p = .002 at Year 2). Motor independence at rehabilitation discharge was associated at one year (ß = .11, p = .03), whilst current social integration (ß = .66, p =.006) and absence of depressed mood (ß = -5.04, p <.001) were associated at two years.

Loss of marital relationship (ß = -.31, p =.03) and depressed mood (ß= -2.14, p =.05) were noted as significant correlates of decrease in life satisfaction between one and two year assessments.

In a study with only 49 subjects, Dawson et al. (2000) attempted to investigate the predictive power of measures of severity of injury on SQOL outcome four years following TBI. Although the sample sizes were very small (Mild TBI n = 25, Moderate TBI n = 8, Severe TBI n = 16) and likely to be a limiting factor in this study, results of multivariate analysis showed the indicator of post-traumatic amnesia to be weakly but significantly correlated (r = -0.30, p = .04) with SQOL. Stepwise multiple regression analysis found the variables age, sex, GCS and PTA predicted 6.9% of variance in SQOL (p < .01). A further point raised in this study was the high rate of participant dropout from this research (almost 50%). These authors noted those participants with least severity of injury were most reluctant to consent to follow-up assessment.

As already mentioned, the only published study to have used the QOLI as a measure of SQOL was conducted by Kalpakjian et al. (2004). This study utilised a small sample of 50 participants with severe TBI (GCS, M = 8.74), an average of almost six years following injury. Measures included the Community Integration Scale, Social Provisions Scale to tap social support, the Positive and Negative Affect Scale to tap depression, a measure of spiritual involvement and beliefs, as well as demographic variables such as age at injury, time since injury, education, ethnicity, sex, marital status, living arrangements, and employment status. Multiple regression analysis identified social support, community integration and positive affect explained almost 50% of SQOL variance.

Warren et al. (1996) examined a sample of 137 people with TBI one year post-injury. Measures included a multidimensional SQOL scale (the Life Satisfaction Index-A), bowel independence and memory items from the Functional Independence Measure (FIM), the Family Satisfaction Scale, self-blame, employment and marital status, as well as age. Multiple regression analysis was utilised to identify a model from these variables explaining SQOL outcome. Results showed a significant model explaining 46% of variance in SQOL ($p < .01$). Significant factors included total family satisfaction (ß = .402), being employed (ß = .158), having memory and bowel independence (ß = .184, ß = .173 respectively) being married (ß = .213), and not blaming oneself for the injury (ß = -.170) significantly increased life satisfaction.

In a study examining a more comprehensive array of variables, Webb et al. (1995) investigated SQOL predictors using path analysis with a sample of 116 people with TBI, two years following their injuries. Variables were included from demographic, psychosocial, physical and rehabilitation domains, and the model accounted for 49% of variance in QOL. Multivariate analysis found employment was the strongest contributor to improved QOL (ß = .358, $p<.001$), followed by family support (ß = -.312, $p<.001$), which reduced impairments and increased functional independence and the likelihood of employment. Whilst this study utilised variables across a range of domains, it did not include cognitive or affective variables. It also relied on a measure of SQOL that had not been validated within the TBI population.

In summary, a small number of studies have attempted to develop predictive models explaining the influence of an array of variables on SQOL.

Studies by Dawson et al. (2000), Kalpakjian et al. (2004), Warren et al. (1996) and Webb et al. (1995) each demonstrated a significant predictive model and accounted for between 6% and almost 50% of variance in SQOL. However, some of these studies suffered limitations in sample size (e.g. Dawson et al., 2000; Kalpakjian et al., 2004). A serious limitation across all studies was the narrow focus on particular predictors. The research reported in this thesis seeks to utilise the findings of this previous research and address these methodological problems within an adequately sized sample, making use of a more comprehensive domain-based approach to identifying predictor variables.

3.2 Key domains affecting SQOL outcomes following TBI

A great number of correlates and potential correlates have been identified within the SQOL research literature. These include demographic and injury-related variables, as well as aspects of physical and emotional functioning. A challenge in conducting research aiming to predict SQOL outcome following TBI is identifying and testing key predictive variables. Whilst it is acknowledged that not all the variables identified in previous research may be feasibly tested in the present research, a domain-based approach is useful in determining the types of variables that may be selected.

Recent reviews have noted specific domains that have been used to describe QOL outcome following TBI (e.g., Berger et al., 1999; Dijkers, 2004; Johnson & Miklos, 2002). Berger et al. (1999) reviewed 16 TBI/QOL outcome studies published since 1991, and recommended further research include examination of variables in physical, psychological, social and cognitive functioning domains. From these reviews, the following five domains describe

key components thought to influence SQOL outcomes following TBI. They include (1) Demographic factors, premorbid and clinical aspects of injury, as well (2) Physical, (3) Psychological, (4) Social and (5) Cognitive functioning. The following subsections/domains present results of previous research that has established the relationships of salient variables with SQOL. Details of measures of these variables are also presented.

3.2.1 Demographic, premorbid and clinical domain

Several studies have examined the effects of variables in this domain on SQOL (e.g., Dijkers, 2004; Kreuter et al., 1998; Novak et al., 2001; Vanderploeg et al., 2003). For example, Novak et al. (2001) examined age, education, employment, substance abuse and social history directly accounted for 8% of the variance in outcome across cognitive, emotional and functional status, 12 months following injury. In contrast, Kreuter et al. (1998) found gender, age at injury, marital status and level of education were not significantly correlated with SQOL. However, a limitation in this study was the use of a global measure of QOL, which required respondents to rate their responses on a visual analogue scale. As discussed in Chapter 2, this method is considered less desirable than use of a multidimensional measure of SQOL, as it risks problems with reliability of responses (Dijkers, 2004). In their study, Kreuter et al. (1998) found time since injury, the level of engagement in work or study, mood (anxiety and depression) physical and social functioning and the severity of the disability were significantly correlated to global QOL following TBI.

In a study comparing two groups of Vietnam-era Army veterans 626 of whom had suffered a mild TBI and 3,896 had no history of head injury,

Vanderploeg et al. (2003) found demographic variables including age, education, and race predicted 23% of variance in post-injury work status and marital status. As already discussed in Chapter 1, participation in these social roles are closely linked to SQOL.

A number of studies have also shown that over time following injury, TBI related problems that act to reduce SQOL have persisted and sometimes increased (e.g., Brown & Vandergoot, 1998; Corrigan et al., 2001; Thomsen, 1994). This is due in part, to exacerbation of secondary problems such as depression and lowered self-esteem (Kendall & Terry, 1996). In addition, pre-injury variables such as history of drug abuse and unemployment have been shown to affect post-injury outcome (e.g., Conneeley, 2003; Corrigan et al., 2001). In summary these variables include gender, age at injury, education level, severity of injury, and time following injury. Following is a summary of relevant research findings for each variable.

- ***Gender.*** A large study by Steadman-Pare et al. (2001) involving 275 subjects, many years following TBI (M = 14 years, SD = 4 years) showed women rated significantly higher SQOL than men on a global scale of SQOL. However, a study by Heinemann and Whiteneck (1995) with a sample of 758 individuals showed no relationship between gender and life satisfaction on a global seven-point scale from 'Delighted' to 'Terrible'. A small study by Seibert et al. (2002) with a small sample (N = 33), up to 24 years following TBI showed women reported poorer QOL than men. Teasdale and Engberg (2005) demonstrated no relationships between gender and SQOL outcome on SQOL measures. A meta-analysis by Farace and Alves (2000) examined outcome

studies looking at depression and a range of other problems following TBI and found women fared significantly worse than males. However, this meta-analysis was limited by the fact that only a small number of studies described differences in outcome for each sex separately. Interestingly, research within the wider population has demonstrated mixed outcomes for gender. Frisch (1994) did not find significant differences for gender in his QOLI normative research. As such, this is a variable that requires further investigation within TBI/SQOL outcome studies using the QOLI.

- ***Age at injury.*** Several studies have demonstrated older people without injuries generally report higher levels of SQOL than younger people (e.g., Brown & Vandergoot, 1998; Novak et al., 2001; Seibert et al., 2002). Age at injury has also been shown to be an important moderator of severity of injury and later psychosocial outcome, with people injured at a younger age demonstrating better outcomes in relation to the severity of injury than older people (Brown & Vandergoot, 1998; Stambrook, Moore, Lubusko, Peters, & Blumenschein, 1993; Teasdale & Engberg, 2005). A review of 18 outcome studies for older adults with TBI by Goleburn and Golden (2001) indicated older adults experience longer periods of hospitalisation and poorer outcomes on measures of functional independence, mood and cognitive functioning. An Australian Institute of Health and Welfare study found older adults who suffered falls were more prominent amongst cases having a long length of hospital treatment (O'Connor, 2002). In the standardisation research conducted on the QOLI by Frisch (1994), a very weak positive relationship was found between age and QOLI Total score, r = .04, $p < .05$.

- ***Education level.*** A large number of studies have shown the greatest proportion of people who sustain TBI have achieved only minimum high school education levels (Drake, Gray, Yoder, Pramuka, & Llewellyn, 2000; Dawson et al., 2000; Harradine et al., 2004; Mailhan et al., 2005; Tate & Broe, 1999; Teasdale et al., 1997; Vanderploeg et al., 2003). Other studies have shown years of education is positively related to key variables of participation, such as employment outcome and thereby affects SQOL following injury (e.g. Klonoff, Costa, & Snow, 1986; Novak et al., 2001; Vanderploeg et al., 2003; Webb et al., 1995). As such, education level is likely to be related to SQOL outcome following TBI.
- ***Severity of injury.*** The relationship between severity of injury, as measured by length of post traumatic amnesia and SQOL outcome, is complex. Studies by Brown and Vandergoot (1998) and Gordon, Brown, and Sliwinski (1998) have reported an inverse relationship between severity of injury and SQOL. However, this is a contentious issue, as more recent research has reported people with mild and severe TBI reporting better SQOL outcomes than those with moderate injuries (e.g., Dijkers, 2004; Mailhan et al., 2005). Mild TBI was associated with poor outcome on psychosocial indicators in 15% to 20% of those sustaining injury (Rappaport, McCullagh, Streiner, & Feinstein, 2003; Ruff, 2005). The study conducted by Dawson et al. (2000) showed duration of PTA had a weak relationship to SQOL, whilst GCS and period of LOC did not. However, as discussed in Section 2.2.1, there were a number of limitations with this study including high attrition of participants leaving a small sample.

- ***Cause of TBI.*** Major causes of TBI include transport accidents, assaults, falls and sports injuries (Fortune & Wen, 1999). No studies were located that examined the effects of the etiology of TBI on SQOL outcome. Some research has investigated specific causes of injury and its correlates, using other outcomes. For example some differences in pre-morbid functioning and outcome following TBI were found in a small (n = 45) study by Schopp et al. (2006). In this research, those who were assaulted were more likely to be male, unemployed and have low income. More favourable outcomes were found for people who were not assaulted. A study by Hicken et al. (2002) found no differences in life satisfaction outcomes for people who sustained TBI in a motor accident compared with those not injured in motor vehicle accidents. Cross and Trent (2003) reported significantly poorer outcomes for fall-related TBI in patients older than 65 years, and indicated outcomes correlated with pre-existing chronic diseases, more severe injuries, longer periods of hospitalisation and increased use of medications. Most sports related head injury results in mild TBI or concussion. However, there is a body of literature describing recurrent TBI, which can lead to more severe TBI due to subarachnoid and intracranial haemorrhaging (Cantu & Voy, 1995; McCrory, Berkovic, & Cordner, 2000; Salcido & Costich, 1992).
- ***Previous significant TBI.*** As discussed in Chapter 1, research has shown that people who sustain significant head injuries often do not recover to pre-morbid levels of subjective quality of life (e.g. Burleigh et al., 1998; Hicken et al., 2002; Kalpakjian et al., 2004). There is evidence that outcomes may worsen for people who sustain repeated traumatic head injuries (Cantu & Voy, 1995;

McCrory et al., 2000). No research was located that had investigated the effect of repeated TBI on SQOL outcomes.

- ***Period of hospital treatment.*** The Australian Institute of Health and Welfare estimate 69% cases are treated for more than one day in hospital following TBI (O'Connor, 2002). Only 11% of people with TBI were admitted for a week or more. The national mean period of hospital treatment following TBI in 1997-1998 was 4.6 days (O'Connor, 2002).

Little research attention has been directed at examination of hospital length of stay on SQOL outcome following TBI. In examination of the relationship of a number of other demographic and clinical variables, Teasdale and Engberg (2005) found no correlation between length of hospitalisation with SQOL measures. Patients' hospitalisation is related in part to their period of post-traumatic amnesia and their recovery of functioning from co-morbid physical and cognitive injuries (Ponsford et al., 1996). As such, it is likely hospitalisation during the time of assessment may be reflected in poorer SQOL rating. Further investigation into any possible relationship between hospitalisation and SQOL outcome is warranted.

3.2.2 Physical domain

TBI can produce neurological impairments that directly effect physical functioning, which in turn affects activity and participation, and life satisfaction (Corrigan et al., 2001; Heinemann & Whiteneck, 1995). Sequelae of mild TBI often include a constellation of temporary symptoms such as headache, dizziness, fatigue, visual problems as well as memory problems and depression that have together been termed post-concussion disorder (King, 1997; WHO,

1978). Moderate to severe TBI may affect mobility and functional independence in activities of daily living (Berger et al., 1999; Ponsford et al., 1996).

In addition to paresis in more severe TBI, a common physical complaint also includes pain. Headache is a common symptom following TBI regardless of severity of injury (Berger et al., 1999; Dijkers, 2004). People with TBI also frequently report increased fatigue (Ponsford et al., 1996), which can affect participation and self-perceptions of endurance (Koskinen, 1998). Research has shown physical complaints predominate soon after the injury, whereas at one to two years following injury, psychosocial complaints such as mood and vocational status are reported to be the most impairing factors (Berger et al., 1999; Dikmen, Machamer, & Temkin, 1993; Webb et al., 1995).

- ***Post-concussion symptoms.*** Research has demonstrated a relationship between persistent symptoms of post-concussive disorder, cognitive deficits, particularly information processing (Bohnen, Twijnstra, & Jolles, 1992) and higher levels of depression and psychosocial dysfunction (Rappaport et al., 2003). Emanuelson et al. (2003) found evidence for this dysfunction affecting SQOL in a study of 173 people with mild TBI. This research noted an inverse relationship between post-concussion symptoms and health-related quality of life.

There have been a number of checklists developed to quantify post-concussion symptoms. Amongst these, the Rivermead Post-Concussion Symptoms Questionnaire (RPQ) has been shown to be a reliable measure of post-concussion disorder (r = .87 to .91) (King et al., 1995). The questionnaire

uses a four-point likert scale to measure the severity of 16 physical symptoms commonly seen following TBI (see Appendix Chapter 3 on Appendix CD).

Several studies have identified high base rates in the report of symptoms of post-concussive symptoms amongst samples that have not suffered head injury (e.g., Gouvier, Uddo-Crane, & Brown, 1988; Wong, Regennitter, & Barrios, 1993). A recent study by Chan (2001), with a sample of 85 people not suffering any head injury or other identifiable neurological or psychiatric disorder has identified base rates for the RPQ. Relatively high percentages of the sample reported problems such as longer time to think 66%, forgetfulness 59%, poor concentration 59%, easily fatigued 54%, and sleep disturbance 51%. There was no effect for gender, nor differences found on neuropsychological tests of attention, working memory, mental fluency and strategy allocation for high or low symptom reporters. Although this study was limited by sample size and a high proportion of females (74%), which is not representative of the TBI population, these results indicate caution is required in interpreting self-reported symptoms of post-concussion symptoms.

Skilbeck and Slatyer (2006 In Press) conducted a confirmatory factor analysis of the RPQ. This study recruited two groups of 254 people who had sustained TBI one month prior to assessment. This research identified four factors that explained 63% of the variance in the first sample, using extraction criteria of Eigen values > 1, and factor loadings > .40. In the confirmatory analysis, data from a second sample of participants was found to fit this initial factor model using structural equation modelling. The four subscales identified and the items loading on each are shown in Table 3.1.

Table 3.1

Factor structure of the Rivermead Post-Concussion Symptoms Questionnaire (Skilbeck & Slatyer, 2006 In Press)

Factor	RPQ Items
Emotion	Poor sleep, Irritability, Depression, Frustration, Restlessness.
Physical	Headache, Dizziness, Nausea, Noise, Photophobia, Fatigue.
Cognitive	Forgetful, Poor concentration, Slowed thinking.
Visual	Blurred vision, Double vision

Note. Rivermead Post-Concussion Symptoms Questionnaire (RPQ)

Functional independence. The Functional Independence Measure (FIM, Uniform Data Systems, 1996) is a well-utilised and researched measure of physical functioning (Ottenbacher, Hsu, Granger, & Fielder, 1996). The FIM consists of 13 items that address self-care and motor functions, and five items that measure cognitive functions. Each item is rated on a scale ranging from one (total assistance) to seven (complete independence). See Appendix Chapter 3 on Appendix CD for an example of the scale. The total FIM score has been shown to have high inter-rater reliability of .95 and a test-retest reliability of .95 (Cohen & Marino, 2000; Huebner et al., 2003; Ottenbacher et al., 1996). Linacre, Heinemann, Wright, Granger, and Hamilton (1994) conducted a Rasch Analysis of the FIM, finding two domains, the Motor domain consisting of 13 items and the cognitive domain consisting of 5 items. This structure is commonly used in TBI research (e.g. Corrigan et al., 2001).

Outcome studies have investigated the link between physical functioning and SQOL. For example, in a prospective study of 218 subjects with TBI, Corrigan et al. (2001) found very weak, non-significant relationships between FIM Motor Independence at discharge to relate to life satisfaction one year following injury, r = .02, and two years following injury r = .01, and with FIM Cognitive at one year, r = .02, and two years, r = .01. In a study with just 25 participants, Huebner et al. (2003) found no statistically significant relationships between FIM scores and a measure of SQOL, following TBI. However, the SQOL measure selected was The Quality of Life Rating (Huebner, Allen, Inman, Gust, & Turpin, 1998), which is limited by not having importance ratings across its 20 domains. The study found the Functional Independence Measure (FIM) was predictive of community participation on the Community Integration Questionnaire, $F(2,19) = 6.15$, p = .009. No published studies have investigated the relationships between the QOLI and FIM.

- ***Pain.*** People experiencing TBI often sustain injuries that cause pain. In milder cases of injury, pain may resolve within hours or days. However, in more severe cases it may persist for weeks or become a chronic problem. Pain is defined as "unpleasant sensory and emotional experience associated with actual or potential tissue damage (International Association for the Study of Pain). However, Branca and Lake (2004) assert pain is a complex phenomena, extending beyond the confines of the body region.

Pain has been shown to be related to problems with a range of outcomes following TBI, including depression (Breslau, Merikangas, & Bowden, 1994), physical functioning (Hicken et al., 2002; Kreuter et al., 1998), and participation

in psychosocial activity (Ponsford et al., 1996). No studies were identified that examined the relationship of pain with SQOL outcome following TBI using a multidimensional measure of importance-weighted satisfaction. However, pain has been shown to relate with important covariates of SQOL, such as depression, which indicates it is likely pain will have an important influence on SQOL outcome following TBI. Visual analogue scales have been shown to be appropriate measures of the subjective experience of pain (Kenny, Trevorrow, Heard, & Faunce, 2006). Branca and Lake (2004) asserted that use of a rating scale for pain from 0 to 10 is a useful measure of the subjective experience of pain.

- ***Fatigue.*** Aaronson, Pallikkathayil, & Crighton define fatigue as "the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization and/or restoration of [psychological or physiological] resources needed to perform an activity". (2003, p.46) Fatigue has been shown to be very common following TBI and to persist over time, particularly for people with more severe injury (Ponsford et al., 1996; Ziino & Ponsford, 2005). Research has shown improvement in fatigue in the first six to twelve months following injury for people with mild TBI (Middlebroe, Anderson, Birket-Smith, & Friis, 1992).

There have been few studies focussed on examining fatigue following TBI. A recent study by Ziino & Ponsford (2005) examined three measurement approaches to fatigue following TBI, in a sample of 49 participants with moderate to severe TBI and healthy controls. Findings were that respondents with TBI reported significantly greater impact of fatigue on their lifestyle and

reported activities requiring physical and mental effort as more frequent causes of fatigue. Greater time since injury was associated with higher fatigue levels, independent of the effects of mood. Age and severity of injury were not found to be associated with fatigue levels. Measures of respondents' experience of fatigue have been successfully measured on visual analogue scales (Ziino & Ponsford, 2005). It is likely fatigue may relate to SQOL following TBI, as it affects engagement in key psychosocial activities.

3.2.3 Psychological domain

Psychological problems related to depression and anxiety are common following TBI (Busch & Alpern, 1998; Deb, Lyons, Koutzoukis, Ali, & McCarthy, 1999; Kreutzer, Seel, & Gourley, 2001; Moldover, Goldberg, & Prout, 2004; Rappaport et al., 2003). Research has attempted to quantify the incidence of affective problems following injury (e.g., Busch & Alpern, 1998; Deb et al., 1999). For example, Deb et al. (1999) found 13.9% of 164 research participants with TBI had a depressive illness compared with 2.1% of the general population, and 9.0% of those with TBI had panic disorder (an anxiety disorder) compared with 0.8% of the general population. Kreutzer et al. (2001) found 42% of participants met DSM IV criteria (American Psychiatric Association [APA], 1994) for a major depressive episode of 722 outpatients with significant TBI, with a mean time since injury of two and a half years. Whilst this study was limited in that it only drew participants from a single outpatient centre, it reflected a cross-section of age, gender, injury severity and aetiology.

In a study examining 170 people with mild TBI, Rappaport et al. (2003) found 15% to be suffering major depression. This well designed study confirmed

poorer outcome for these depressed individuals across multiple domains including perseverance of post-concussive symptoms and psychosocial dysfunction. In their review, Busch & Alpern (1998) confirmed this relationship between post-concussion symptoms and depression.

In this interesting review of 21 studies examining depression following TBI, Busch and Alpern (1998) indicated consistency in the prevalence of depression symptoms meeting DSM criteria in samples of people with mild TBI, at approximately 35%, and can endure for many years following injury. These authors also found several studies that demonstrated a relationship between cognitive deficits and depression (e.g., Downhill & Robinson, 1994; MacNiven & Finlayson, 1993).

Key features of depression include melancholia or sadness, and anhedonia, which is an inability to experience pleasure from normally pleasurable life events such as eating, exercise, and social interactions (APA, 2000). In TBI outcome research, depression has been linked to social isolation and withdrawal, poorer motivation and persistence in relation to psychosocial activities such as maintaining work, leisure and rehabilitation activities (Gloag, 1985; Kaitaro, Koskinen, & Kaipo, 1995).

Studies of outcome following TBI have also identified the strong role of affective problems hindering psychosocial functioning and reducing SQOL. For example, in a long-term follow-up of 15 individuals with severe TBI, Koskinen (1998) showed problems with depression affected most respondents and were related to SQOL. Other prospective studies by Corrigan et al. (2001) (reviewed in the previous section) and Kreuter et al. (1998), noted absence of depressed

mood at one to two years following TBI was highly related to SQOL outcome. These studies utilised samples of 218 and 92 people with TBI respectively. Kreuter et al. (1998) found an inverse relationship between depression and global SQOL with significant correlation of -.56, at a median of 9 years following injury.

In the conceptual model explaining determinants of subjective well-being outlined in Chapter 2, Frisch (1994) explained life satisfaction or SQOL has a two-way relationship with affect. This conceptualisation of the strong relationship between affect and SQOL has been confirmed by empirical research. For example, Abbey & Andrews (1985) showed depression accounted for almost 50% of variance in SQOL amongst a large sample taken from the general population. Within the TBI/SQOL research literature Corrigan et al. (2001) found depressed mood at two years following injury (n = 218) was the most significant predictor of SQOL explaining 17% of the variance amongst an array of other variables. Another small study examining 19 adults with severe TBI, Vickery, Gontkovsky, and Caroselli (2005) found a strong correlation between the Beck Depression Inventory (Beck, Steer, & Brown, 1996) and QOLI (Frisch, 1994), r = .67, p < .01.

Anxiety often co-occurs with depression and can have an impact on the course of depressive illness, prolonging episodes of major depression (Kessler, 2001). Underhill et al. (2003) examined differences in life satisfaction between groups of depressed and non-depressed adults at 2-years, 4-years and 5-years following TBI, finding significantly poorer ratings for depressed respondents, t (322) = -9.67, p < .0001 at two years following injury, and similar differences at

the other time-points. The relationship of people's experience of anxiety following TBI and SQOL using the QOLI has not been examined in published studies. However, a study by Eng et al. (2005) has shown moderate correlations, r = .32 to .45, between the QOLI domains and several measures of anxiety in a sample of 138 people suffering social anxiety.

A measure of anxiety and depression symptoms that has been extensively validated in healthy, psychiatric and neurological populations is the Hospital Anxiety and Depression Scale (HADS, Snaith & Zigmond, 1994). This scale was originally developed for use with physically ill patients in the hospital context, but has also been extensively used in community settings. Only a small number of published studies have used this scale with TBI samples (e.g. (Kreuter et al., 1998; Powell, Heslin, & Greenwood, 2002).

HADS items ask respondents to rate the intensity or frequency of specific problems and activities over the preceding week. There are fourteen items, rating seven symptoms each of anxiety and depression (Snaith & Zigmond, 1994). The maximum score for each mood state is 21. Scores of 10 or below fall within the normal/non-clinical range. Clark and Fallowfield (1986) reviewed the validity and reliability of the HADS and found these to be satisfactory. Further details of the psychometric properties of the HADS are provided in Study 4.3, in Chapter 10. An example of this scale is attached in the Appendices of Chapter 3 on the Appendix CD.

There has been extensive research examining the factor structure of the HADS items, with studies confirming a two-factor structure, and others finding a three-factor structure. For example, Mykeltun, Stordal, & Dahl (2001) found a

two factor solution best fitted the data from over 51 000 non-clinical respondents, whilst others have found a three factor solution was the best fit to the data in normal and a range of clinical samples (e.g., Dunbar, Ford, Hunt, & Der, 2000; Martin, 2005). As such, it is important to consider both the traditional two-factor structure of the scale and consider any factor structures relevant to the particular clinical sample.

There is very little published research that has examined outcome within the TBI population using the HADS. One study by Hellawell et al. (1999), with a sample of 96 consecutively recruited adults from a neurological rehabilitation unit, with moderate and severe TBI, found a slight increase in prevalence of anxiety and no difference in prevalence of depression following injury. A summary of results of this study is shown in Table 3.2

Table 3.2

Percentage of sample reporting moderate and severe levels of anxiety and depression (Hellawell et al., 1999).

	Severe head injury	Moderate head injury
Anxiety		
6 months	20%	26%
12 months	24%	27%
24 months	11%	19%

Table 3.2 (continued)

	Severe head injury	Moderate head injury
Depression		
6 months	8%	4%
12 months	12%	11%
24 months	10%	6%

Hellawell et al. (1999) also reported strong correlations between anxiety scores and depression scores across six-month, twelve-month and two-year follow-up points, $r = .60$, $p < .01$ to $r = .70$, $p < .01$.

In a recent study, Holm and Skilbeck (2006) conducted exploratory and confirmatory factor analysis of the HADS items within a representative sample of 372 participants following TBI. Three factors were confirmed in Table 3.3 below.

Table 3.3

Factor structure of the of the Hospital Anxiety and Depression Scale (Holm & Skilbeck, 2006)

Factor	HADS items
Psychomotor	1. I feel tense or wound up.
	6. I feel cheerful.
	7. I can sit at ease and feel relaxed.
	8. I feel as if I am slowed down.
	11. I feel restless as if I have to be on the move.
	14. I can enjoy a good book, radio or TV programme.
Anxiety	3. I get a frightened feeling, something awful may happen.
	5. Worrying thoughts go through my mind.
	9. I get a frightened feeling like butterflies in the stomach.
	13. I get sudden feelings of panic.
Depression	2. I still enjoy things I used to enjoy.
	4. I can laugh and see the funny side of things.
	10. I have lost interest in my appearance.
	12. I look forward with enjoyment to things.

Note. Hospital Anxiety and Depression Scale (HADS)

Other studies have confirmed a three-factor model for the HADS in clinical samples such as facial disfigurement (Dunbar et al., 2000), older adults with acquired amputations (Desmond & MacLachlan, 2005), as well as a study with a large sample (n = 2574) from the general population (Dunbar et al., 2000). Depression and anxiety are very important covariates with SQOL, and prevalent following TBI.

3.2.4 Social domain

Social participation is related to SQOL outcome following TBI and can be seriously compromised following TBI (Brown et al., 2003; Dijkers, 1999). The social domain includes participation in community activity such as work, avocational or voluntary activity, relationships with family and friends and leisure activity. Challenges to resuming work activity following TBI include problems related to physical and cognitive deficits as well as emotional problems, such as depression or irritability (Drake et al., 2000; Johansson & Bernspang, 2003; Ponsford et al., 1996). These impairments have been shown to create a significant burden of care for close relatives of the injured individual, which can cause problems in intimate relationships and with relationships with family and friends (Duggan, 2000; Kreuter et al., 1998; Novak et al., 2001; Teasdale et al., 1997). In addition, restricted participation in leisure activity due to limited finances, mobility problems and depressed mood following TBI have been shown to relate to reduced SQOL (Koskinen, 1998; Steadman-Pare et al., 2001).

Brown et al. (2003) compared the extent of engagement in social-recreational activity in 279 individuals with TBI with matched control subjects

with no disability (n = 224), finding the non-disabled group was more active than the TBI group. For people with TBI, greater social-recreational activity was associated with being single, higher income, less depression, more vocational hours, and greater time since injury. Participation in social activity has been equated with community integration (Brown et al., 2003; Kalpakjian et al., 2004).

- ***Community integration.*** A measure of community integration designed to assess functional independence in the home and community after TBI is the Community Integration Questionnaire (CIQ, Willer, Linn, & Allen, 1994). The CIQ is a widely used measure of participation outcomes for TBI (e.g., Huebner et al., 2003; Wood & Rutterford, 2006), with good psychometric properties. It consists of a 15-item scale, measuring three subscales or domains – Home Integration, Social Integration, and Productivity (see Chapter 3 on the Appendix CD).

The CIQ was initially piloted with 49 adults with severe TBI, and normative data has been developed with other TBI samples (e.g., Brown et al., 2003; Corrigan & Deming, 1995; Novak et al., 2001). The CIQ's subscales include:

- *Social Integration,* which is composed of items related to socialisation with others and activities outside of the home, which is rated according to frequency of activity and companionship during the activities (e.g. with friends, family, or with others who have brain injuries).
- *Home Integration,* containing items related to activities in the home such as household cleaning, cooking, childcare and financial management, and is

rated on whether the person performs the activity independently, with another person or not at all.

- *Productivity,* which is made up of items related to time spent outside the home per week, in employment, school and volunteer activities. The total score ranges from 0 to 29. Higher scores indicate greater community integration (Huebner et al., 2003).

CIQ scores have been found to relate to SQOL. In a recent study with only 50 subjects with severe TBI, Kalpakjian et al. (2004) reported significant relationship between CIQ Total score and QOLI Total score (r = 0.58, p < .001).

Socio-economic status: Research has shown people from lower socio-economic groups are at greater risk of injury (Moodie, 2001). Socio-economic status has been shown to relate to SQOL in the general population and in the quality of outcomes across a range of clinical populations (e.g., Hoofien, Vakil, Gilboa, Donovik, & Barak, 2002; Louis & Zhao, 2002).

Conceptually, socio-economic status has been described as a complex construct that includes aspects of education level, vocational skill, income and wealth (Sinclair, Doughney, & Palermo, 2001). A large number of measures and classification systems have been devised in attempts to capture the complexity of this construct. The Australian Bureau of Statistics (ABS) has developed and evaluated a number of these measures (ABS, 2006). A commonly used, skill-based classification system is the Australian Standard Classification of Occupations (ASCO, ABS, 1997). This classification system contains nine major groups and is further explained in Chapter 11.

- ***Work capacity:*** Engagement in work has been shown to relate to SQOL (Corrigan et al., 2001; Steadman-Pare et al., 2001). In an interesting review of 23 studies based on the general population, Rice, Near, and Hunt (1980) found that satisfaction with work was positively but only modestly correlated (r = .20 to .40) with overall life satisfaction. In a recent TBI study, Johansson & Bernspang (2003) asserted the feelings of worth and satisfaction that come from role performance and productivity may increase the QOL experience. Outcome studies show that while a larger proportion of people with mild TBI appeared to regain employment within weeks or months of injury, only a third to a half of those with moderate to severe TBI who were working or studying at the time of injury regained competitive employment (Brooks, 1992; Dikmen et al., 1993; Tate et al., 1989).

Within the TBI/SQOL outcome context, a qualitative study by Tempelmann (2000) found four people with severe TBI discussed returning to work as a strong contributor to their QOL, even though job satisfaction may have been low. Other longer-term outcome studies such as that conducted by (Webb et al., 1995) found employment was the strongest contributor to improved QOL two years following injury. This study with 186 participants showed regaining work explained 36% of the variance on a multidimensional SQOL measure.

- ***Relationship status.*** In general population studies, a satisfying relationship with a significant other has generally been shown to increase SQOL (e.g. Frisch, 1999). However, following significant TBI, changes in physical and emotional functioning place strain on such relationships. Problems in marital relationships following TBI have been extensively documented (see Ponsford et

al., 1996). Some researchers have noted that whilst relationships may not end in early years, many deteriorate and eventually cease in the longer term, particularly when injuries are more severe (e.g., Kreuter et al., 1998; Koskinen, 1998; Thomsen, 1994). In three separate studies, loss of spouse relationship was related to lower life satisfaction (Corrigan et al., 2001; Klonoff et al., 1986; Vanderploeg et al., 2003).

3.2.5 Cognitive domain

Sequelae of TBI can include a range of cognitive impairments (Ponsford et al., 1996; Schretlen & Shapiro, 2003). These include problems with aspects such as attention, memory and learning, as well as aspects of executive functioning, such as ability to divide attention, and slowed information processing (Ponsford et al., 1996). Problems with cognitive functioning have been shown to have broad reaching effects on aspects of psychosocial functioning, self-confidence, and can disrupt work, relationships and leisure activities (Dikmen, Machamer, Powell, & Temkin, 2003; Ponsford et al., 1996).

A number of studies have established the pattern of cognitive recovery and outcome following TBI. Schretlen and Shapiro, (2003) conducted a well designed review and meta-analysis of 39 cognitive outcome studies published between 1984 and 2003, with 1716 people who sustained TBI and 1164 control participants. This study confirmed that cognitive functioning for people who sustained mild TBI returned to pre-injury levels of functioning within one to three months following injury. People with moderate to severe TBI show most improvement in cognitive functioning in the first two years following injury, but

their level of functioning remains significantly impaired, compared with pre-injury estimates (Schretlen & Shapiro, 2003).

Research has also investigated cognitive functioning following TBI on aspects of SQOL, such as return to work and community integration. Drake et al. (2000) investigated factors predicting return to work for a group of 121 respondents following mild TBI, finding age and three cognitive variables – verbal memory (California Verbal Learning Test), verbal fluency (Controlled Oral Word Association Test), and speed test of planning and strategy (Wisconsin Card Sorting Test) predicted return to work status accurately 69% of the time, with a 66% correct classification rate. In another study with 289 TBI participants, with a mean time post-time of eight years, Doninger, Heinemann, Bode, Corrigan, and Moore (2003) found cognitive tests of memory and judgement (from the Neuro-behavioural Cognitive Status Examination, Kiernan, Mueller, Langston, and Van Dyke (1987) were weakly correlated with aspects of community integration (CIQ, Willer, Ottenbacher, & Coad, 1994), $r = .19$, $p < .01$, and $r = .19$, $p < .01$, respectively. In more severely injured individuals, memory functioning has been shown to predict return to work (Tate & Broe, 1999). This study highlighted the role of cognitive functioning in psychosocial role performance following TBI and the usefulness of neuropsychological assessment in identifying those at risk of poorer outcome.

A number of qualitative studies have identified that people with TBI report perceptions of ongoing problems with aspects of their overall quality of life. For example, Corrigan, Whiteneck, and Mellick (2004) surveyed a group of 1802 people, one year following TBI, finding the most frequently expressed needs

were "improving your memory, solving problems better" 34.1%. In a large survey of severely injured participants five, ten and fifteen years following injury Teasdale & Engberg (2005) also found most commonly reported problems were related to people's perception of their cognitive impairments. However, there have not been many studies that have reported on relationships between cognitive impairment with subjective quality of life.

A study by Mailhan et al. (2005) objectively and subjectively investigated relationships between aspects of disability such as physical abilities, cognitive functioning and self-esteem and life satisfaction in a cohort of 75 participants with severe TBI, two years following injury. The main findings of this study were that the relationship between life satisfaction and disability was not linear, as those with moderate problems rated poorest life satisfaction and those with severe problems rated life satisfaction at a similar level as the good recovery group. This suggests there are a number of other factors that may moderate the effects of objectively measured aspects of cognitive functioning on people's perceptions of their quality of life.

Few studies have reported relationships of specific objective measures of cognitive functioning with measures of SQOL. However those that have, showed there was little strength in direct relationships of cognitive test performance on SQOL following TBI. Klonoff et al. (1986) investigated cognitive functioning on aspects of QOL for 71 people two to four years following TBI, finding motor functioning, memory, and constructional ability were related most strongly to QOL. However, the study used the Katz Adjustment Scales as a measure of

SQOL. Several researchers criticized the use of this measure in TBI research as not being a valid measure of SQOL (e.g. Teasdale & Caetano, 1995)

In a study limited by use of a global measure of SQOL, Steadman-Pare et al. (2001) used Trails B as a single measure of residual cognitive impairment in a study aimed at identifying factors associated with perceived QOL. This study enrolled 275 participants who were on average 14.2 years post-injury at interview. Trails B was shown to be weakly correlated with QOL, $r = -.14$, $p < .05$. In this study, much stronger relationships were found with "General mental health" $r = .63$, $p < .001$ and measures of level of handicap, such as "Getting along with other people", $r = -.45$, $p < .001$.

In summary, very little research has reported the relationships of specific cognitive measures with SQOL following TBI. Results of the few studies in this area indicate it likely that only weak relationships may be identified between tests of attention, memory and executive functioning and SQOL. However in both studies, significant limitations were identified in the use of inappropriate SQOL measures. In a recent study focussed on participants with severe TBI, Mailhan et al. (2005) indicated it is likely the relationships between cognitive test scores and SQOL are not linear and that there are factors that mediate in this relationship. It remains important for variables in this domain to be investigated to determine relationships between cognitive variables and SQOL as measured by the QOLI (Frisch, 1994; Frisch, 2004). Common sub-domains of cognitive functioning are pre-injury estimation of cognitive functioning, attention, memory and learning and executive functioning (Groth-Marnet, Gallagher, Hale, & Kaplan, 2000). Relevant tests of each of these sub-domains are presented and

discussed below. These tests were recommended as measures of choice as they are most popular and useful in TBI rehabilitation and research settings (Ponsford et al., 1996; Spreen & Straus, 1998). Their psychometric characteristics are presented in Chapter 12. Examples of the tests are presented in Chapter 3 Appendices on the Appendix CD.

Pre-injury estimate of cognitive functioning.

- *National Adult Reading Test* (NART): The NART was devised by Nelson, (1982) as a test of an over-learned skill that was highly correlated with intelligence and would provide a pre-injury estimate of cognitive functioning (Spreen & Strauss, 1998). Performance on the NART is thought to depend more on previous word knowledge than on current cognitive capacity. This scale provides an indication of pre-injury level of cognitive functioning.

Attention.

Attentional processes have an important role in learning and memory functioning as well as other cognitive processes (Spreen & Strauss, 1998). Mateer and Mapou (1996) proposed separating attention into two major areas: deployment and encoding. Deployment includes aspects of arousal, focus, and sustained attention. Aspects of deployment may be assessed to some extent by tests of executive functioning such as Trails B (Spreen & Strauss, 1998), which is later discussed in detail. Encoding refers to how well an individual can retain information and then process it. Two tests that specifically examine verbal and visual encoding capacity are:

- *Digit Span* (Weschler Adult Intelligence Scale III, (WAIS III, Weschler, 1997). This task requires the participant to repeat a fixed random series of

numbers of increasing length spoken by the researcher. In addition to a forward span, a backward span is evaluated by having the participant repeat digits in reverse order. Groth-Marnet et al. (2000) indicate Digit Span is more likely to measure attentional capacity than aspects of memory.

- *Visual Patterns Test* (VPT, Della Salla, Gray, Spinnler, & Trivelli, 1998). The VPT is a measure of short-term visual memory. It was developed to assess the purely visual component of short-term memory. The task involves the participant viewing a pattern of black squares within a matrix for three seconds. The stimulus is withdrawn and the participant responds by marking squares within a blank matrix denoting the position of the stimulus black squares.

Memory and learning.

Independence in activities of daily living relies on memory and learning functioning. Problems in this area of functioning can have negative impact on psychosocial functioning. A battery incorporating tests designed to detect and evaluate memory impairments is the Adult Memory and Information Processing Battery (Coughlan & Hollows, 1985). More information about this battery is provided in Study 4.5 in Chapter 12. The memory tasks test both visual and verbal learning as follows:

- *List Learning* (Coughlan & Hollows, 1985). This test assesses rote learning of verbal information and susceptibility to interference. The participant first attempts to learn a list of words over five trials. Asking the participant to recall of this original list following a one-trial attempt at a different list, assesses susceptibility to interference. This test is derived from the Rey Auditory Verbal

Learning Test (Rey, 1964), but has a slower rate of presentation of two seconds per word.

- *Design Learning* (Coughlan & Hollows, 1985). This test assesses the rote learning capacity of visual information and susceptibility to interference. It was intended as a visual modality parallel of the List Learning task. The participant attempts to reproduce a small diagram over five trials. Susceptibility to interference is measured by requesting recall of the original design following a one-trial attempt at a different design.

Executive functioning.

Executive functioning includes all the tasks associated with performing a novel problem-solving task from its inception to completion (Groth-Marnet et al., 2000). Such functions may include awareness that a particular problem exists, an evaluation of the problem, the formulation of specific goals, development of plans to address the problems and evaluation of the effectiveness of those plans as well as management of the process of progressively implementing and evaluating those plans. Various tests of executive functioning have been developed. Those chosen for this study reflect clinical deficits in aspects of executive functioning that may impact on aspects of psychosocial functioning and SQOL, and include:

- *Speed of information processing* (Coughlan & Hollows, 1985): Designed to measure the efficiency of mental processes, this task was based on a cancellation task with as little demand as possible on memory, reasoning, visual perception, and motor-coordination. It requires participants to locate and cross out the second highest number in a row of numbers and continue this for four

minutes. A comparison for pure motor-speed is provided in completion of a second rapid-cancellation-without-visual-search task.

Letter-Number Sequencing (Weschler Adult Intelligence Scale III, Weschler, 1997): This task requires participants to sequentially order a series of letters and numbers presented aurally, in a mixed up order (Kaufman & Lichtenberg, 1999). The task was originally developed by Gold, Carpenter, Randolph, Goldberg, and Weinberger (1997) as a measure of working memory functioning. Letter-Number sequencing has been shown to load onto the Working Memory Index (Groth-Marnet et al., 2000), and is thought to measure aspects of working memory, attention and sequencing ability (Kaufman & Lichtenberg, 1999).

- *Controlled Oral Word Association Test* (COWAT): This test evaluates the spontaneous production of words beginning with a given letter within a limited time (usually 60 seconds). Normally the letters F, A, and S are used; however other letters have also been used in the past (Spreen & Straus, 1998).

- *Trails B*: (Spreen & Strauss, 1998): Trails B requires the ability to maintain and integrate two series of simultaneously while alternating between them. The Trails B test has circles numbered 1 to 13 or lettered A to L, which must be connected by the participant, who draws a line that alternates between these numbers and letters in sequence. The score is the time to completion of the task, measured in seconds. A better score is reflected in a shorter time taken to complete the task. Steadman-Pare et al. (2001) found Trails B to be weakly related to global SQOL ratings following TBI. It is a procedure of the Halsted-Reitan battery.

3.3 Summary and research directions

In general, sequelae of TBI negatively affect functioning across broad domains of SQOL. TBI/SQOL outcome research is an emerging area, in which preliminary studies have identified a number of the salient variables predicting outcome. A number of limitations of previous research have been identified. These have included limited sample sizes, inappropriate use of measures of SQOL and neglect of the broad array of predictor variables.

As such, there is a need within the TBI/SQOL field for further research to address these problems and investigate the contribution of a comprehensive range of variables across the key domains outlined in this chapter. It is the intention of this thesis to report the results of studies aimed at identifying a predictive models of SQOL outcome at time-points to one year following TBI. The process of developing this model progresses through a series of studies that examine the QOLI within the TBI population, then identify the most salient variables for predictive modelling of SQOL outcome. An outline of studies reported in this thesis follows:

- Study 1. The QOLI was tested as an outcome measure in the evaluation of a structured TBI rehabilitation intervention.
- Study 2. Examination of the QOLI within an Australian TBI sample, examining pre-injury estimates of SQOL and comparing the normative distribution of this Australian TBI sample with the US-based QOLI standardisation study. This study also identifies and compares factor structure of the QOLI with other clinical groups.

- Study 3 reports results of outcome research using the QOLI.

The remainder of this thesis provides research to determine the relationships of the variables already described in the present chapter, leading to a predictive model of SQOL following TBI.

- Study 4 separately investigates outcomes on variables within each of the five domains discussed in the present chapter, and their relationship to QOLI outcome.
- Utilising the results of the preceding studies, Study 5 identifies and tests predictive models of SQOL outcome following TBI.

The next chapter presents the first study of this thesis.

CHAPTER 4

STUDY 1 - FACILITATION OF ADJUSTMENT FOLLOWING TBI: EVALUATION OF A PROGRAMME APPROACH

This chapter provides details of the methodology and results of the first study reported in this thesis. Study One reports results of an evaluation of a pilot rehabilitation programme for adults with traumatic brain injury (TBI), and trialled the Quality of Life Inventory (QOLI, Frisch, 1994) as a global measure of adjustment to injury. The opportunity to carry out this study arose in 1998, with the first Potential Unlimited Programme (PUP). A summary of this research was published (Thomas, 2004, see Appendix N1 Chapter 4 on the CD)

The PUP was a joint programme of the Southern Area Brain Injury Service (Goulburn, NSW) and Outward Bound Australia, a well-recognised outdoor experiential education provider. This programme incorporated outdoor experiential education (OEE) and group work with the aim of facilitating aspects of adjustment to traumatic brain injury (TBI). This chapter proceeds with details of the conceptual model used to define the process of adjustment to TBI and an overview of the development and structure of the programme.

4.1 Definition of adjustment to traumatic brain injury: Simpson's model

As discussed in Chapter 1, Simpson (1996) provided a theoretical model that describes a framework for understanding the process of adjustment to TBI. This model was developed to guide counsellors working within the context of adjustment to TBI, and here provides an operational definition of adjustment to TBI. It contains four tasks of adjustment, described as follows:

1. ***Understanding:*** refers to acquiring an awareness of impairments and associated disabilities.
2. ***Re-integrating identity:*** refers to the integration of old and new aspects (pre and post injury) of the person into a valued sense of self.
3. ***Acceptance:*** involves processing the emotional impact of the injury, its sequelae and the ongoing process of recovery.
4. ***Restructuring:*** involves modifying and adapting pre-injury skills and acquiring new skills in areas of relationships, employment and independent living.

Simpson (1996) indicates these tasks may not necessarily proceed in any particular sequence, but gains in one area may initiate gains in other areas of the model. This framework for understanding the process of adjustment to TBI provides a foundation for evaluation of both the PUP and the QOLI in this first study.

4.2 The effectiveness and limitations of outdoor experiential education

Studies have found a range of benefits in OEE with clinical and disabled populations, including traumatic brain injury (Lemmon, LaTourrette, & Hauver, 1996). Additionally, meta-analyses have examined hundreds of OEE programmes with non-clinical groups. These show moderate effect sizes of approximately .3 to .5 on a range of relevant outcome variables, across a number of studies (e.g., Cason & Gillis, 1994; Hans, 2000; Hattie, Marsh, Neill, & Richards, 1997). In general, the literature examining the efficacy of OEE points to its value as an adjunct to mainstream rehabilitation services.

An important study conducted by Hattie et al. (1997) examined 151 unique samples located within 96 adult experiential education studies (excluding clinical and disabled groups) and reported that the average effect size at the end of the programmes was .34 on self-concept variables. This was followed by an additional effect size of .17 between the end of the programme and follow-up, representing a total effect size of .51. This gain is high compared with other educational programmes, where an effect size of .25 is considered a sound gain, and provides significant justification for OEE programmes (Hans, 2000).

Amongst much of this literature, the Outward Bound movement is recognised as a major service provider in the OEE field. The movement commenced during World War II, and now operates 52 centres worldwide. Outward Bound courses are structured to provide a range of challenging group-based outdoor experiential activities, such as abseiling, climbing, caving, high ropes course, rafting, bush-walking and camping. On these activities, small groups of participants (six to ten) have opportunities to extend their conceptions of their capabilities through learning to exercise positive, functional approaches to practical and social problems, whilst taking on increasing levels of independence and responsibility. At the core of Outward Bound philosophy is the idea that if a person can learn something of their capacities and is motivated towards fulfilling their potential, they will be able to manage more effectively in a range of contexts, regardless of their circumstances (Richards, 1977; Zelinski & Shaeffer, 1991).

Only one previous programme evaluation was identified with a specific focus on adults with TBI utilising an Outward Bound course. This study by

Lemmon et al. (1996) reported on outcomes for a group of twelve professional women with mild traumatic brain injury, who attended a three-day programme with Outward Bound in Colorado, USA. In their article, Lemmon et al. (1996) indicated the purpose of their programme for participants was "...to increase self-esteem, self-confidence, respect for one's limitations, and understanding of one's strengths." (p.16). A sustained increase on four of twelve scales was reported (e.g. Understanding of strengths and limitations, and Self-esteem, at one-year post-programme). The effects of the programme on other outcome variables such as ability to get along with others, and ability to persevere with frustrating tasks were decreased over time.

Investigations of the efficacy of outdoor adventure therapy programmes suggest that these programmes provide people from clinical and disabled populations with opportunities to increase self-awareness, self-esteem and improve social skills (e.g., Anderson, Schleien, McAvoy, Lais, & Seligmann, 1997; Lemmon et al., 1996; Luckner & Nadler, 1995). On closer examination, clear links were noted in some studies with three of the tasks presented within Simpson's conceptualisation of adjustment to injury. It was reported that participants gained a clearer *Understanding* of personal strengths and limitations (Lemmon et al., 1996), used this knowledge in tasks of *Identity Reintegration* (Anderson et al., 1997), and came to an *Acceptance* of life events related to living with the sequelae of injury (Luckner & Nadler, 1995).

Whilst it appears Outward Bound programmes may facilitate many of the tasks identified in Simpson's model, poor maintenance of the positive effects of such courses for participants is a well-known and documented problem,

particularly for participants from clinical and disabled populations (eg. Kaplan, 1990; Kessel, Resnick, & Blum, 1985). These authors concluded that to maintain the benefits of these courses, the outdoor courses should not be relied upon as an end in themselves, but be incorporated into a larger overall programme (Kaplan, 1990; Kessel et al., 1985). As such, follow-up groups should be offered to support the integration of learning and transfer of changes in participant's values, self-image and skills from the OEE programme into their life in the community (Kaplan, 1990; Luckner & Nadler, 1995). However, no evidence was found in the literature of such a follow-up group programme being implemented or evaluated with participants with TBI.

Additionally, no evidence was seen in the literature suggesting that Simpson's crucial task of *Restructuring* would likely be addressed on OEE courses. As already outlined, *Restructuring* involves modifying and adapting pre-injury skills and acquiring new skills in areas of relationships, employment and independent living (Simpson, 1996), and may be seen as a crucial task in the ongoing psychosocial and community functioning of people with TBI. It was proposed that a follow-up group programme would provide opportunities for Simpson's task of *Restructuring* to be directly addressed, and might best facilitate the maintenance of participant's gains from an Outward Bound course.

4.3 The structure of the Potential Unlimited Programme

Utilising much of the theoretical background already described here, TBI rehabilitation staff at the Southern Area Brain Injury Service in conjunction with instructors at Outward Bound Australia developed the Potential Unlimited Programme (PUP). The PUP was trialled with two groups of adults with TBI in

1998 and 2000. Both programmes were undertaken from Outward Bound Australia's National Base at Tharwa, in the Australian Capital Territory.

The programmes consisted of three stages as follows:

- Stage 1 involved clarification of programme objectives with participants and group based fundraising activities. Participants worked together to raise a substantial proportion of the required funds from their local community in order to pay for the Outward Bound course.
- Stage 2 involved participants on a nine-day Outward Bound "Discovery" course. These standard "Discovery" courses, offered by Outward Bound Australia, were adapted to the particular group requirements to accommodate participants' mobility and communication needs. The courses provided a range of challenging individual and group outdoor activities such as rafting, abseiling, rock climbing, and high ropes course, as well as having to attend to activities of daily living in a basic camping environment. Participants were instructed in the required skills and were encouraged to take on increasing levels of responsibility, within safe guidelines, to achieve various group and individual objectives.
- Stage 3 included follow-up group work aimed at assisting participants to transfer personal insights and gains from the outdoor programme into the achievement of personal goals in key areas of psychosocial functioning. These included work on improving relationships, vocational and leisure activities, and increasing independence, such as moving out of home or regaining a driver's licence. Fortnightly meetings of around two hours duration, over a three to four

month period were facilitated by rehabilitation staff, who had also attended the Outward Bound course with the participants. The focus of these meetings was on participants' engaging in *Restructuring* tasks (Simpson, 1996) through activities such as achievement of individual goals, problem solving, further life planning, and social skills development.

4.4 Aims and hypotheses

This pilot study had three main aims for which hypotheses were generated. Firstly, this study aimed to determine whether participants who attended the pilot Potential Unlimited Programmes (PUP) experienced changes related to adjustment to TBI and SQOL, in both the short and longer term following their involvement in the programme. Based on the conceptual analysis of the structure of the PUP being likely to facilitate aspects of adjustment to TBI described in Simpson's model, it was hypothesised that programme participants would indicate significant and sustained increases in perceived quality of life, compared with a demographically matched group who did not attend these programmes

Secondly, this pilot study sought to explore the nature of changes identified by participants. This required a qualitative approach involving group and individual interviews. Thematic analysis of these interviews was structured to inform the qualitative results and arranged using the framework of Simpson's model of adjustment to TBI. It was hypothesised participants attending these programmes would indicate experiencing gains in psychosocial adjustment in line with Simpson's model of adjustment to TBI.

Finally, this study aimed to examine the utility of the third stage (Follow-up group work) of the programme, by comparing the SQOL outcomes of participants who regularly attended group sessions in Stage 3 of the programme with those who chose not to. Based on analysis of the structure of the programme in facilitating Simpson's tasks of adjustment, it was hypothesised participants who attended the follow-up group programme in Stage 3 would demonstrate a higher quality of life, over a longer period than programme participants who completed Stages One and Two, but chose not to attend this stage of the programme.

4.5 Design

This pilot longitudinal study involved collection of both quantitative and qualitative data was conducted with experimental and control groups. The experimental group contained adult participants from two PUPs, while the control group comprised demographically matched adults who did not attend any such programme. Exploration of programme outcomes identified by participants was undertaken through individual and group interviews and data concerning participant's subjective quality of life were collected at multiple points in time as shown in Table 4.1.

Table 4.1

Interview Time Points and Questionnaire Data Collection Intervals

Time points	Description
Time One	Baseline, prior to the commencement of a programme.
Time Two	Immediately following the completion of Stage 2 of a programme.
Time Three	At the completion of Stage 3 of a programme. PUP 1998 individual participant interviews PUP 2000 participant group interview
Time Four	Six months following completion of a programme. PUP 2000 individual participant interviews
Time Five	Two years following completion of a programme. PUP 1998 individual participant interviews

4.6 Participants

Participants in this study were adult volunteers with TBI who were past or present clients of a service of the NSW Brain Injury Rehabilitation Programme (BIRP). Participants in both the experimental and control groups were independently mobile and capable of self-care in activities of daily living.

Participants in the experimental group volunteered to participate in one of two programmes:

1. Potential Unlimited Programme commenced in 1998 (PUP 1998) (Males = 4, Females = 2).
2. Potential Unlimited Programme commenced in 2000 (PUP 2000) (Males = 7, Females = 1).

In recruiting participants for these programmes, invitations were sent to past and present clients of participating services of the NSW Brain Injury Rehabilitation Programme (BIRP). Approximately 200 invitations to participate in PUP 1998 were mailed to past and present adult clients of the Southern Area Brain Injury Service.

A voluntary control group was recruited from adults with brain injury who indicated initial interest in participating in the first programme (PUP 1998), but were not able to attend for a variety of reasons such as work or family commitments. This control group undertook surveys at identical times as Experimental group (PUP 1998) participants.

The control group comprised six male and two female adults with brain injury, with demographics similar to those of the experimental group. Participants in both groups were of similar functional independence, being independently mobile and capable of self-care. Demographic information for the experimental and control groups is provided below in Tables 4.2, 4.3 and 4.4.

Participants ranged in age from 18 to 56 years (M = 31.54 years, SD = 10.37 years). Eleven experimental group participants suffered brain injury through accidents involving head trauma, whilst two suffered cerebrovascular accidents and one suffered neurotoxic poisoning. The mean length of time since

injury for experimental group participants was 5.99 years (*SD* = 4.54 years, Range = .55 to 15.02 years).

Table 4.2

Descriptive Statistics of Participants' Age, Age at Injury, and Time Since Injury

	Experimental Group (*N*=14)		Control Group (*N*=8)	
	M	*SD*	*M*	*SD*
Current age	31.54	10.37	38.38	12.14
Age at injury	25.54	11.18	33.50	12.71
Time since injury	5.99	4.54	4.97	2.28

Whilst no statistically significant differences were found between the experimental and control groups on any of the demographic variables, the control group was slightly older and were injured at a slightly greater age than experimental group participants.

Table 4.3

Distribution of Participants' Cause and Severity of Injury

	Experimental group		Control group	
	n	%	n	%
Cause of injury				
Traumatic brain injury	12	85	6	75
Cerebrovascular Accident	1	7	2	25
Neurotoxic poisoning	1	7	0	0
Severity of injury				
Mild	2	14	2	25
Severe	1	7	3	37
Very severe	2	14	0	0
Extremely severe	8	57	3	37

Table 4.3 shows most experimental and control group participants suffered traumatic brain injury, while one member of the experimental group suffered neurotoxic poisoning from agricultural chemicals.

All participants reported losing consciousness in connection with their experience of brain injury, except the subject who suffered neurotoxic poisoning. The length of time that participants experienced post-traumatic amnesia (PTA) was used to indicate the severity of brain injury in accordance with the classification system outlined by Ponsford et al. (1996) and Russell (1977).

The length of time in PTA of experimental group participants ranged from zero to 128 days, indicating variation from mild to extremely severe brain injury, with most participants having experienced extremely severe brain injury. The participants in the control group were distributed across the range of severity of injury.

Table 4.4

Participants' Pre-injury and Baseline Vocational and Marital Status, and Baseline IQ

	Experimental group				Control group			
	Pre-injury		At baseline		Pre-injury		At baseline	
	n	%	*n*	%	*n*	%	*n*	%
Vocational status								
Paid work	11	78	1	7	8	100	3	38
Voluntary Activities	1	7	5	36	0	0	0	0
Studying	2	14	3	21	0	0	0	0
Home duties	0	0	5	36	0	0	5	63
Marital status								
Single	9	64	9	64	3	38	3	38
Live with partner	5	38	4	29	4	50	3	38
Separated	0	0	1	7	1	13	2	25

Table 4.4 (continued)

	Experimental group				Control group			
	Pre-injury		At baseline		Pre-injury		At baseline	
	n	%	*n*	%	n	%	n	%
Baseline IQ								
Borderline and Low Average ranges	NA		8	57	NA		2	25
Average and High Average ranges	NA		4	29	NA		6	75
Not Available	NA		2	14	NA		0	0

Note. NA = Not Available.

Table 4.4 shows most of the participants had been involved in paid work or voluntary activities prior to brain injury, but few were employed at the Time 1 data collection. In the experimental group, all had been working prior to their injury, and three were employed at Time 1. Most experimental group participants were single, whilst two of five participants who had been living with a partner, had separated since their brain injury. The control group contained a spread of single, married and separated participants.

Most recent neuropsychological reports, obtained with participants' permission, indicated that a little more than half of the experimental group participants' level of intelligence was in the Borderline to Low Average ranges. Data for two experimental group participants were not available. The control

group contained a larger percentage of participants in the Average and High Average ranges than the experimental group.

Several of the experimental group participants also suffered from physical problems. Three participants suffered chronic pain affecting their heads, shoulders and backs. Five participants suffered hemiplegia. All participants were independently mobile and able to maintain self-care.

4.7 Instrumentation

The Quality of Life Inventory (QOLI) was administered at each time point of the study as described in the procedure below. A full description of the QOLI is provided in Chapter Two. Notably there was some variation in procedure. The PUP 2000 group did not return questionnaires at Time Five. At Time 1 the informed consent and complaints contact procedure as required by the NSW Health Human Research Ethics Committees, survey instructions and demographic information form were administered. These components as well as interview and transcription equipment are detailed below.

4.7.1 Informed consent procedure

Participants and their guardians (where appropriate, and with participant's knowledge) were advised of the aims and nature of this study, that the questionnaires would be administered over the specified time points and that they could choose to participate in group, and individual interviews to discuss their experience of the programme with the researcher. A questionnaire cover sheet contained this information and a place for participants to sign, confirming their consent to participate in this study (see Chapter 4 Appendices on Appendix CD). A separate consent form detailing participant's involvement in interviews

was also provided and participants signed this to provide consent to participate in individual and group interviews (see Chapter 4 Appendices on the Appendix CD).

4.8 Procedure

Interviews conducted with individual participants were audio taped using a compact recorder. The telephone conference call provider recorded group interviews on audiotape. All interviews were confidentially transcribed for analysis purposes. Questionnaires were administered and individual and group interviews took place across five occasions between the baseline assessment conducted prior to the programme and two years following completion of the programme (see Table 4.1).

On being administered questionnaires, participants were advised that participation was voluntary and that they could withdraw from the study at any time. They were advised that their completion and return of questionnaires reflected their ongoing informed consent to participation in the study. Participants were informed that their responses were completely confidential and the questionnaires would take up to 30 minutes to complete. The instructions on the front of the questionnaires were highlighted when administered. Prior to commencing any interviews participants were informed that participation was voluntary and that they could cease or withdraw from an interview at any time. Participants were informed of the uses and processes of analysis of interview data, and that their responses would be kept completely confidential. The complete output of these analyses is presented in the Chapter 8 folder on the Appendix CD.

4.8.1 Collection and analysis of qualitative data

In addition to participating in questionnaire surveys, participants in the PUP 1998 group were individually interviewed on completion of the programme. The PUP 2000 group engaged in a group interview on completion of the Outward Bound course and in the last group meeting of the Follow-up programme.

The qualitative data were sought to provide an in-depth understanding of participants' perceptions of their outcomes from the programmes. The interviews were semi-structured, participants were asked standard questions (see copy of questions in Chapter 4 Appendices) about perceived outcomes from the Outward Bound course and Follow-up programme, with a subsequent discussion exploring participant's responses. These interviews were recorded on audio-cassettes, transcribed and subjected to thematic analysis (See Berg, 1998; Orford, 1992). External supervision from Prof. Paul Morrison, (Head of the School of Nursing, University of Canberra) was provided for each stage of this process.

The process of analysis began with the identification of themes arising from the text of each participant's interview transcript. Various categories were identified amongst these themes, and a separate word processor document file was opened for each category. A table was created in each category/document file, listing the themes identified from each participant's transcript, the participant's statement and referencing information.

4.9 Results

The results of this evaluation are presented in two sections. First, as a global indicator of adjustment to TBI, trends and comparisons between and within the experimental and control groups on the QOLI are provided, over the time points of the study. Second, a summary of the results of the thematic analysis of interview data of participant-reported-outcomes is presented. As this analysis distinguished the roles of the OEE course and follow-up programme in facilitating separate tasks of Simpson's model of adjustment to TBI, these are presented under these headings. In addition, QOLI outcomes comparing participants who regularly attended the follow-up group programme with non-attendees are presented.

4.9.1 Quality of life analysis

As no statistically significant differences were observed between the PUP 1998 and PUP 2000 groups at any time point of the study, results for these two groups are combined. QOLI T-score distributions, corresponding QOLI ranges and effect sizes are provided in Table 4.5. Differences between the experimental and control groups over the data collection points of the study were examined using t-tests. Similarly, t-tests were used to examine differences within the experimental group at each data collection point in relation to participant's baseline scores at Time 1. Group mean effect sizes were also generated at each time point in the data collection, from Time 2 and compared with Time 1 means.

Table 4.5

QOLI T Score Distributions, Effect Sizes and Range Trends

Group		Time 1	Time 2	Time 3	Time 4	Time 5
Experimental	*N*	14	14	14	14	5
	M	35.36	42.57*	38.29	46.14**	50.00*
	SD	8.80	11.08	10.56	12.22	13.95
	ES		.68	.28	1.04	1.75
	Range	V Low	Low	Low	Ave	Ave
Control	*N*	8	8	8	4	6
	M	38.63	39.63	39.00	20.25	41.83
	SD	21.97	19.66	18.88	14.73	10.36
	ES		.11	-.05	-.10	-.18
	Range	Low	Low	Low	V Low	Low

*$p < .05$. **$p < .01$ (compared with Time 1 scores). *Note.* The only significant difference between the experimental group and comparison group occurred at Time 4, $p = .03$.

Table 4.5 shows significant increases in mean QOLI T scores within the experimental group between Times 1 and 2, t (13) = -2.80, $p < .05$, Times 1 and 4 t (13) = -3.72, $p < .05$, and Times 1 and 5, t (13) = -3.35, $p < .05$, on paired samples t-tests. No significant differences were observed between the Time 1 group mean and the means at other time points within the control group. A significant difference was found between the experimental and control group at Time 4 t (16) 3.59, $p < .01$, using independent samples t-tests. As noted, the

small number of respondents in the control group at Time 4 may have accounted for the group mean falling in the Very Low range, compared with means in the Low range at all other data collection points, and so should be ignored. Mean effect sizes are also provided. For experimental group participants, a moderate mean effect size was observed between Times 1 and 2, reducing between Times 1 and 3. Very large effect sizes are then seen between Times 1 and 4, and 1 and 5. These effect size trends are seen to correspond with the trends across the QOLI ranges. Little or no change was observed in the control group QOLI mean effect sizes across the time points of this study.

4.9.2 The OEE Course and Follow-Up Groups in facilitating adjustment

A major finding of the thematic analysis of participant interview data indicated the OEE course had provided opportunities for participants to engage in three tasks of Simpson's model of adjustment to TBI, these being *Understanding*, *Reintegrating Identity* and *Acceptance* (Simpson, 1996). Participants indicated the follow-up group programme had provided opportunities for engagement in Simpson's fourth task of *Restructuring* (Simpson, 1996). This was congruent with predictions found in the earlier review of the literature. A summary of the thematic analysis of participants' comments on their perceptions of outcomes of the programme is presented within the framework of Simpson's model of adjustment to injury.

4.9.3 The role of the OEE course

Understanding: Refers to developing a personal awareness of capabilities, impairments and associated disabilities.

Participants reported that they gained insight into personal strengths, limitations, and unexpected capabilities as a result of engaging in programme activities. In reflecting on the whole programme experience, participants commented, '...it made us realise what we could and couldn't do' and 'It has taught me personally how much I can do, how far I can go, not to just sit there and go "...I can't do this" or I can't do that"'. Participants specifically reported gaining insights into physical capabilities and limitations, emotional issues such as anger and fear management, mental and social areas including problem solving and discovering leadership abilities through engaging in challenging group activities on the Outward Bound course.

Re-integrating identity: Refers to the integration of old and new aspects (pre and post injury) of the person into a valued sense of self.

Participants identified changes in areas such as locus of control, increases in their feelings of competence and confidence, as having made a positive impact on their sense of identity. Several participants noted a strong shift in locus of control from an external base, where they once assumed people and/or circumstances had greatest control in their lives to an internal base, where they now feel they can take control and responsibility for the direction of their life. For example, 'I used to rely on everyone else. [Now]...if it doesn't work or if it doesn't happen, I have only got myself to blame'. In relation to their experiences of the Outward Bound course, participants noted an increase in

self-esteem, for example '...after the camp I definitely was feeling more confident'. Participants reported gaining insights resulting from their demonstrated, yet unexpected competence on course activities and related this learning to challenges in their lives. Participants also indicated they had adopted new themes such as 'I can do it' and 'Have a go', for example 'Our disabilities can't stop us doing anything, if we put our minds to it we can do anything, we just have to try'.

Acceptance: Refers to processing the emotional impact of the injury, its sequelae and the ongoing process of recovery.

Participants reported that the Outward Bound course had facilitated their processing of accepting the impact of their injuries on their lives. Participants indicated this occurred by taking a positive approach to managing problems, and accepting circumstances over which participants perceived they had minimal control. For example one participant said '[I've learned that]...instead of worrying about something you can't control, put your thoughts into doing something positive'. Other participants indicated learning more effective coping strategies through peer tutoring from other group members. For example '...I looked at other people and how they coped...I could see they were satisfied...I've probably learned to be satisfied with what I've got.'

4.9.4 The role of the Follow-Up Group

Restructuring: Refers to modification and adaptation of pre-injury skills and acquisition of new skills.

Participants reported the Follow-up group provided a number of useful functions, as they sought to define and pursue personal goals. These included

reinforcement of personal learning from the Outward Bound course and group support in defining and achieving personal goals, for example one participant stated, 'Meeting every fortnight encouraged me to continue with setting and achieving my goals and facing my fear in achieving goals'. Additionally, participants reported receiving benefits from supporting each other in practical and personal ways, boosting each other's motivation and helping each other to continue to manage their fear in attempting their goals in areas of psychosocial functioning.

The usefulness of offering the Follow–up group programme to participants was investigated by examining differences in mean QOLI scores between those participants who attended Stage 3 activities regularly, and those who attended less than half the meetings. Group trends in group distributions, and effect size comparisons across the time points of the study are presented in Table 4.6.

Table 4.6

QOLI Distributions and Effect Sizes for Participants Who Regularly Attended Stage 3 Follow-up Group Meetings and Those Who Chose Not To Attend

Group		Time 1	Time 2	Time 3	Time 4	Time 5
Stage 3 Attendees	*n*	9	9	9	9	4
	M	34.89	45.11**	37.44	48.78**	55.00*
	SD	9.97	10.42	12.27	11.86	9.63
	QOLI Range	V Low	Ave	Low	Ave	Ave
	ES		.98	.22	1.33	2.13
Stage 3 Non Attendees	*n*	5	5	5	5	1
	M	36.20	38.00	39.80	41.40	30.00
	SD	7.19	11.87	7.53	12.66	.
	QOLI Range	V Low	Low	Low	Low	V Low
	ES		.16	.39	.50	.23

*$p < .05$. **$p < .01$ (compared with Time 1 ratings)

Table 4.6 provides a comparison in QOLI distribution and effect sizes between participants who regularly attended, and those who chose not to attend Stage 3 Follow-up group activities, as part of the PUPs. Although only four of the fourteen participants chose not to regularly attend Stage 3 Follow-up group activities, they were seen to experience little change in quality of life scores over the course of the study, remaining in the Very Low and Low QOLI ranges. Participants who did attend Stage 3 meetings showed significant increases in

their quality of life between Times 1 and 2, t (8) = -3.76, p < .01, Times 1 and 4, t (8) = -5.72, p < .001, and Times 1 and 5, t (8) = -4.74, p < .05. Very small numbers of participants were available at Time 5 for this analysis, as only the PU 1998 group had returned data.

Very large effect sizes were observed for participants who regularly attended this stage of the programme between Times 1 and 4 (six-months after completion of the PUPs), and Times 1 and 5 (two years after completion of the PUPs). Mild to moderate change was observed in effect sizes for non-attending participants.

4.10 Discussion

This evaluation of the Potential Unlimited Programme sought to test three hypotheses. These were:

1. Programme participants would indicate significant and sustained increases in perceived quality of life, compared with a demographically matched group who did not attend these programmes.
2. Participants attending these programmes would indicate experiencing gains in psychosocial adjustment in line with Simpson's model of adjustment to TBI.
3. Participants who attended the follow-up group programme in Stage 3 would demonstrate a higher quality of life, over a longer period than programme participants who completed Stages One and Two, but chose not to attend this stage of the programme.

Significant and sustained improvements were noted in programme participants' subjective quality of life scores over the data collection points of the

study. Effect sizes for participants were much higher than expected, compared with the previous meta-analysis studies evaluating OEE programmes, which predicted effect sizes of .3 to .5. This can be explained by the fact that the majority of participants returned scores in the Very Low QOLI Range at the Baseline (Time 1) data collection, and returned scores in the Average Range at six-month and two-year follow-up (Times 4 and 5). The QOLI manual indicates an increase in scores, shifting from one range to the next to be clinically significant. The average shift of participants from the Very Low Range, to be sustained in the Average Range at follow-up data collections indicates significant adjustment to TBI.

Through individual and group interviews, participants indicated significant gains in psychosocial adjustment to TBI. Their comments reflected many fundamental values and principles for effective living, such as gaining understanding of strengths and limits in a variety of areas, learning to manage emotions such as fear and anger, shifting to an internal locus of control and taking responsibility for life outcomes, coming to an acceptance of issues beyond personal control, developing goal setting and problem solving skills, as well as learning the value of 'trying' in various aspects of their lives, perseverance, and social networks. Many of these were practiced and mastered over the course of the programmes.

Participants who attended the majority of the Stage 3 Follow-up groups were seen to reflect most improvements on the QOLI compared with those few who chose not to attend. Qualitative analysis within Simpson's task of *Restructuring* highlighted the value of the follow-up group programme in

facilitating this task of adjustment, by providing opportunities for participants to reflect upon learning from the Outward Bound course, set and refine personal goals, solve problems and share resources, as well as encourage each other in the pursuit of their goals.

The only other identified programme evaluation of an Outward Bound course, with a focus on outcomes for people with TBI involved women with mild traumatic brain injury in a three day programme Lemmon et al. (1996). Post-hoc analysis of Potential Unlimited Programme outcomes noted several participants had suffered Very Severe and Extremely Severe TBI, as determined by length of PTA (see Table 4.3), and many were functioning in the Low Average and Borderline Range of intellectual functioning. The outcomes of this study suggest this programme approach may benefit participants with a range of levels of cognitive functioning and severity of TBI.

4.10.1 Limitations of Study 1 and directions for further research

The early stage of development and nature of the PUP lead to a number of limitations in this pilot study. These included the small number of self-selected participants, and recruitment of a control group with some differences on injury-related variables (e.g., age at injury) than those in the experimental group. As such, it is possible that factors other than those associated with the PUPs may have had some influence on the QOLI scores of participants in this pilot study. Another important limitation to this study was the use of a generic measure that was previously unreported in outcomes studies within the TBI population. Each of these limitations will be addressed in greater detail below.

It is possible that demographic and other differences between the experimental and control groups may have been confounded with QOLI outcomes in this programme evaluation. Control group participants who chose not to participate in the PUP may have done so for a variety of reasons. It is possible these factors may have influenced aspects of psychosocial variables known to affect perceived quality of life such as individuals' work, relationships, leisure activities, self-concept, locus of control, willingness to take risks, and ability to sustain motivation. Ultimately, these differences may have worked to constrain improvement in perceived quality of life over the time points of the study both for participants in the control group and those participants who elected not to attend the follow-up group stage of the programme. With very small samples in these groups, it is difficult for these samples to specifically and exclusively account for changes in quality of life related to the programmes, over the extended time frame of the data collection.

There may have been differences between the generic, US-based normative distribution of the QOLI and the Australian samples of people with TBI. This is seen in the lower mean QOLI scores for both experimental and comparison groups at Time 1 (see Table 4.5). Unlike other chronic conditions such as spinal cord injury where life satisfaction has been shown, over time, to return close to pre-injury levels (Cummins, 2005), several studies have noted lower life satisfaction persisting for many years following TBI (e.g. Burleigh et al., 1998; Corrigan et al., 2001; Garske & Thomas, 1992). This suggests the need to validate SQOL measures within the Australian TBI population. With international TBI rehabilitation and outcome research now focussed on SQOL outcomes, a

clear need identified in this study is the provision of reference and normative data for the TBI population.

In Study 1, the QOLI appeared sensitive to changes in SQOL. This sensitivity was confirmed by the changes indicated by participants in the qualitative analysis. As such, the QOLI may be considered a valuable measure of SQOL following TBI, with applications in both clinical and longitudinal outcome research. However, Study 1 also highlighted the need for the QOLI to undergo validation within the Australian TBI population before further outcome research proceeds. This further research may be guided by TBI Consensus Group recommendations for validation of quality of life measures within the TBI population (e.g., Bullinger, 2002).

Further research is necessary to provide a point of reference for clinical and outcome research purposes by examining pre-injury estimates of SQOL of people with TBI. The following two studies reported in this thesis provide normative reference information for the QOLI within a large Australian TBI sample. More specifically, Study 2 provides pre-injury estimates of SQOL and the structure of the QOLI within a group of recently injured Australian adults with TBI. Study 3 used the QOLI to provide normative data across a longitudinal study of SQOL outcome following TBI. With these reference points established, Studies 4 and 5 examine the correlates of longitudinal SQOL outcome, and develop predictive models of SQOL outcome up to twelve months following TBI.

CHAPTER 5

STUDY 2 - ESTIMATION OF PRE-INJURY SUBJECTIVE QUALITY OF LIFE IN TRAUMATIC BRAIN INJURY

Results of Study 1 suggest there may be important differences between the TBI population and the general population in rating subjective quality of life (SQOL) following injury. These low SQOL ratings found in Study 1, at the baseline data collection, compared with the normative population have been similarly reported in several other TBI outcome studies using other measures of SQOL (e.g., Burleigh et al., 1998; Corrigan et al., 2001; Garske & Thomas, 1992).

Prior to conducting Study 1, only one other published study was identified in which results of the Quality of Life Inventory (QOLI, Frisch, 1994) were reported within the TBI population. As explained in Chapter 2, this study by Kalpakjian et al. (2004) examined the QOLI scores of 50 people with severe TBI (Mean GCS=8.74), more than five years after their injuries. Kalpakjian et al. (2004) reported a mean QOLI score in the Low-Average range (T-score M = 43.08, SD = 17.24). The mean QOLI score of this TBI sample appeared much lower than that of the non-disabled standardisation sample. This was generally consistent with other TBI/SQOL research, which used SQOL measures other than the QOLI (e.g., Brown & Vandergoot, 1998; Hicken et al., 2002; Webb et al., 1995).

Epidemiological studies show people with TBI are predominantly male, with minimum education (Hillier et al., 1997; Tate et al., 1998). Highest incidence of TBI occurs in the young and elderly (Fortune & Wen, 1999). As such, the

findings of SQOL outcome studies, including those of Study 1, raise questions about the possible premorbid differences between the TBI population and general population, and add weight to recent calls within the TBI/SQOL literature for the validation of generic SQOL measures within the TBI population (e.g., Bullinger, 2002; Dijkers, 2004; Johnson & Miklos, 2002; NIH, 1999). Another important area of research that has not yet been investigated within the TBI population is the factor structure of the QOLI. Indeed to date, there has been no published confirmatory factor structure for the QOLI in any clinical or normal population.

As described in Chapter 1, the ultimate goal of this thesis was focussed on identifying predictive models of SQOL outcome following TBI. In summary, the results of previous research and the lack of validation of the QOLI as a measure of SQOL within the TBI population clearly indicated the requirement for further research. As such, two preliminary studies (Studies 2 and 3) were designed to provide reference information about the QOLI within this population.

The present chapter reports the methodology, results and implications of Study 2, which undertook analysis based on pre-injury estimates of SQOL by respondents surveyed shortly after injury. Pre-injury estimations of SQOL provide essential points of reference in both outcomes research and clinical contexts, such as rehabilitation programme evaluation. This study also sought to address the question of the utility of importance-weighting of satisfaction scores. Review of the literature in Chapter 2 highlighted the conflict between SQOL/TBI reviews that call for use of measures with importance-weighting of satisfaction facilities and other researchers who argue importance-weighting is of little

benefit. Additionally, this study sought to confirm the factor structure of the QOLI within this population, for use in further analysis.

5.1 Aims

No specific hypotheses were generated for this preliminary study, as findings of the few studies conducted in this area have been disparate. Relying on the QOLI as a measure of SQOL, this study aimed to:

1. Compare the generic US-based distribution provided by Frisch (1994) and the Australian sample of people providing estimates of their SQOL prior to their TBI. This comparison also aimed to provide reference information for the local TBI population.
2. Determine the factor structure of the QOLI within this population using both exploratory and confirmatory analyses.
3. Address the question of the effect of importance-weighting of satisfaction scores by comparing the factor structures of the QOLI using both importance-weighted satisfaction scores and satisfaction scores without importance weighting.

5.2 Design

This study utilized a cross sectional design, which sampled adults who had recently sustained a TBI. Data was collected as soon as possible following participants' injury and emergence from post-traumatic amnesia (PTA). The sample was split into two sub-samples according to order of enrolment to the study. Separate exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) methods were employed with each group.

5.3 Participants

Participants were adult volunteers who had recently sustained TBI and who had consented to involvement in the TBI Outcome Study operated by the Neurotrauma Register of Tasmania (NTR, Slatyer & Thomas, 2005). The NTR commenced a population-based prospective TBI outcome study in December 2003. The project attempted to recruit all patients meeting specific criteria relating to TBI, who presented to the Department of Emergency Medicine and other wards at the Royal Hobart Hospital, Australia. Eligibility criteria for inclusion in the NTR outcome study included any period of loss of consciousness, transient confusion or concussive symptoms following trauma involving the head, or which could cause TBI (Slatyer & Thomas, 2005). Assessments were conducted in the offices of the NTR, within the inpatients wards, and on domiciliary visits. Participants were screened with the Mini Mental Status Examination (Folstein, Folstein, & McHugh, 1975), and scored 23 or greater for inclusion.

Participants comprised 470 people who had sustained a TBI within the past month. Approximately two thirds of the group was male (65%). Participants' mean age at injury was 34.75 years (*SD* = 16.44), and ranged from 16 to 84 years. The median age at injury was 30.64 years. Participants' reported having received an average of 11 years of education (*SD* = 2.31). Intellectual functioning prior to injury was estimated using the National Adult Reading Test (NART), and showed a normal distribution. Mean estimated pre-injury IQ was 96.84 (*SD* = 11.23), and the median was 97.20. These demographic characteristics were typical of TBI groups studied in previous epidemiological research (e.g., Hillier et al., 1997; Tate et al., 1998).

Transport related accidents (39%) and assaults (29%) were the two most frequent causes of injury, followed by falls (18%) and sports injuries (6%). Approximately 8% of participants suffered a TBI from other causes. In comparison with two previous Australian epidemiological studies, conducted in South Australia (Hillier et al., 1997) and on the north coast of NSW (Tate et al., 1998), traffic accidents accounted for 40-50% of TBI, followed by falls (20-30%), and leisure/sports injury (25%). In both these studies assault accounted for approximately 9% of TBI, a much smaller proportion than that reported in the present Tasmanian sample. The previous two epidemiological studies used a similar methodology to the present study in sourcing participants, as such it is disturbing to note this increased proportion of TBI attributed to assault.

Several sources suggest that since these epidemiological studies were conducted in the late 1980s, the rate of reported violent crime, including assault has increased substantially. For example, Moffat and Poynton (2006) indicate a 105% increase in the rate of assaults reported each year in New South Wales since 1990. These researchers found the rate of reporting had remained unchanged over this period and concluded this rise in as an indicator of a genuine increase in the incidence of assault. Tasmanian Police statistics indicated a similar rate of increase in person related offences, including assault, up from 3 676 in 2000/2001 to 5 271 in 2004/2005 (Tasmania Police, 2006b).

As shown in Table 5.1, approximately half the participant group sustained a mild TBI. Just under one third suffered a moderate head injury and a fifth received a severe TBI.

Table 5.1

Severity of traumatic brain injury (classifications based on Russell, 1977)

Severity	Duration of PTA	n	%
Very Mild	< 5 minutes	125	28
Mild	5 to 60 minutes	108	24
Moderate	1 to 24 hours	127	28
Severe	1 to 7 days	65	14
Very severe	1 to 4 weeks	23	6
Extremely severe	> 4 weeks	2	0

In comparison with the two previous Australian epidemiological studies, the proportions of people suffering TBI of varying severity were approximately matched. Tate et al. (1998) reported proportions as 62% mild, 20% moderate, and 14% severe, and Hillier et al. (1997) reported 82% mild, 9% moderate and 9% severe using similar PTA duration criteria. The Tasmanian sample had a slightly greater proportion of more severely injured participants.

5.4 Instrumentation

The Quality of Life Inventory (QOLI, Frisch, 1994) was used to provide indications of participants' SQOL. A detailed description of the QOLI and its psychometric properties is provided in Chapter 2.

5.4.1 *Informed consent procedure*

Participants provided informed consent to participation in line with the consent procedures established for the Neurotrauma Register of Tasmania

(NTR). Where participants were less than 18 years of age, their guardians were provided a separate Information Sheet and Consent Form (see Appendix Chapter 5 on the Appendix CD). All were given a full explanation of the nature and aims of this study, and were informed of the voluntary nature of their involvement. Participants confirmed their consent to participation in this study by signing the Consent Form.

5.5 Procedure

In recruiting participants to this study, staff working for the NTR TBI Outcome Study initially interviewed all people notified to the project by the Department of Emergency Medicine at the Royal Hobart Hospital, as soon as practical after their injury. Participants scored 23 or greater on the Mini Mental Status Examination, provided consent to involvement in the study and attended an interview with research staff. The interview confirmed participants' eligibility, and assessed a range of cognitive, physical and psychosocial variables including pre-injury estimates on the QOLI. The median time following injury until participants were assessed was 16 days (*SD*=27.31). Participants' QOLI raw scores were calculated and converted to T-Scores (M = 50 and SD = 10), for comparison with the normative distribution provided with the QOLI (Frisch, 1994).

Exploratory factor analysis (EFA) was undertaken with the first 235 participants in the data set, using a principal axis factor analysis with varimax rotation (Tabachnick & Fidell, 2001). To ensure extracted factors accounted for reasonably large amounts of variance, criterion were set at Eigen values greater than one. Determination of significant domain-factor loading was set at a

coefficient level of .4 or greater, as this provided a level at which there was least sharing of domains between factors, balanced with meaningful psychological interpretation of the resulting structure.

Prior to analysis, the implications of the importance-weighted scoring system of the QOLI were considered. Some researchers have suggested the product of importance scores can interfere with psychometric properties of an SQOL scale such as the QOLI (e.g. Trauer & Mackinnon, 2001). To test this, an EFA was conducted firstly using QOLI total raw scores that were a product of importance and satisfaction ratings (where 0=Not important, 1=Important, 2=Extremely important) and satisfaction ratings (where -3=Extremely dissatisfied, -2=Somewhat dissatisfied, -1=A little dissatisfied, 1=A little satisfied, 2=Somewhat satisfied, 3=Extremely satisfied). A further analysis using only QOLI satisfaction scores was then conducted for comparison. The complete output of these analyses is presented in the Chapter 5 folder on the Appendix CD.

5.6 Results

The results of this study are presented in three sections. First, the distribution of the pre-injury estimations of Tasmanians who had recently suffered a TBI are presented and compared with the generic US-based normative distribution. Relationships between pre-injury estimates and key demographic variables are examined. In the second section, an exploratory factor analysis of the first 235 participants in the sample provides a comparison of the structure of importance-weighted satisfaction and satisfaction only scoring structures of the QOLI. The final section provides results of a confirmatory factor

analysis of the structure of the QOLI utilising the remaining 235 participants responses.

5.6.1 Pre-injury QOLI Distribution

Table 5.2 compares the pre-injury ratings of adult Tasmanians who had recently sustained a TBI compared with the US-based generic distribution of the QOLI.

Table 5.2

Comparison of Normative Statistics for the QOLI

	Tasmanian TBI sample		Generic US-based	
	(*N*=470)		(*N*=798)	
	Raw	T-Score	Raw	T-Score
Mean	2.51	49.39	2.60	50.00
Standard Deviation	1.70	13.09	1.30	10.00
75th percentile	3.63	57.92	3.40	57.00
Median	2.75	51.15	2.70	51.00
25th percentile	1.66	42.77	1.80	43.50
Minimum	-3.94	-.29	-3.88*	NA
Maximum	5.88	75.19	5.88*	NA
Skew	.11	.11	NA	NA
Kurtosis	.75	.75	NA	NA

* Taken from clinical samples provided by (Frisch et al., 1992). *Note.* NA=Information not available.

In general, the distributions of the participant group of the present study were similar to the generic US-based normative distribution provided by Frisch (1994). The Tasmanian TBI sample was well distributed across the range of possible QOLI scores. Slightly greater variation was noted within the Tasmanian TBI sample, compared with the generic US-based distribution. The mean of the Tasmanian TBI sample lay at the 46th percentile, compared with the US-based generic distribution. No difference was found between groups on a one sample t-test, t (393) = 1.02, p = .31.

Table 5.3 compares the raw score ranges of the generic US-based distribution with the Tasmanian TBI sample, within the clinical ranges of the QOLI. These ranges are described in the QOLI Manual (Frisch, 1994).

Table 5.3

Comparison of Pre-injury Raw Score Estimates of Tasmanians with TBI with the Generic US-based Classifications

Overall QOL Classification	Raw scores Ranges		T-Scores Ranges	Percentile Range
	TBI	US-generic		
High	3.95 to 6.00	3.60 to 6.00	58 to 77	81st to 99th
Average	1.57 to 3.94	1.60 to 3.50	43 to 57	21st to 80th
Low	0.47 to 1.56	0.90 to 1.50	37 to 42	11th to 20th
Very Low	-6.00 to 0.46	-6.00 to 0.80	0 to 36	1st to 10th

The comparison in Table 5.3 highlights the differences between the US distributions and Tasmanian TBI distributions. The score required to enter the High Range is marginally greater in the Tasmanian TBI sample. There is a greater spread of scores within the Average Range. The Low and particularly the Very Low Range scores extend below the scores of the US-distribution. As such, a lower score is required to enter the Very Low ranges within the Tasmanian TBI distribution compared with the generic US distribution. However these differences are minimal.

An independent samples t-test showed no difference in QOLI scores for gender, t (461) = -1.37, p = .17. Correlational analysis showed a very weak relationship with Age at Injury (r = .12, p = .01). A significance level of p <.01 was adopted for this and subsequent analyses. No other relationships between QOLI total scores (pre-injury estimates) and years of education, pre-injury IQ estimates on the NART, and the severity of TBI sustained by the respondent as measured by length of PTA, were observed.

Interestingly, weak positive relationships were identified between NART scores and Age at Injury, r = .32, p <.001, and NART scores and Years of Education, r = .35, p <.001. Independent samples T-tests were used to examine for differences in predicted IQ (NART scores) for Age at Injury and Years of Education. First, the sample was split into two groups at the median of Age at Injury (30.64 years). A significant difference was found in predicted IQ between these age groups, t (314) = 3.49, p<.01, with the younger group having a lower mean predicted IQ (M = 94.67), than the older participants (M = 99.00). The sample was then split at the median for years of education (11 years) and a

significant difference found for participants' predicted IQ on the NART, t (309) = 5.32, $p < .01$). The mean VIQ of the group with 11 or more years of education group was 99.97 (SD = 10.39), whilst the mean of those with less than 11 years of education was 93.45 (SD = 11.24). These differences indicate that further analysis of the relationships between demographic and other key variables is required to understand QOL data. A more detailed examination of these relationships is reported in Study 4, Chapter 8.

5.6.2 Exploratory Factor Analysis

The results of the exploratory factor analysis with the first 235 participants in the sample are presented in Table 5.4 and 5.5. Acknowledging the conflicting views about the value of importance weighting of satisfaction scores, the factor structure of domain importance-weighted satisfaction were compared with domain satisfaction scores.

Table 5.4 presents the structure of the QOLI, using importance-weighted satisfaction scores. In this rotated solution, three factors met criteria for extraction, with Eigen values greater than one, accounting for a total of 53% of the variance. As already explained, a factor loading greater than .40 provided a threshold level that provided the most meaningful structure.

Table 5.4

Factor Structure of the QOLI Using Importance Weighted Satisfaction Scores

Domains	Factors		
	I 37% variance (Family & environment)	II 9% variance (Self actualisation)	III 7% variance (Self-functioning & activity)
Health	.01	.13	**.57**
Self Esteem	.33	.18	**.59**
Goals & Values	.37	**.44**	**.44**
Money	**.45**	.22	.36
Work	.17	.31	**.44**
Play	.10	**.44**	**.57**
Learning	.12	**.74**	.23
Creativity	.35	**.60**	.18
Helping	.23	**.55**	.25
Love	**.45**	.25	.23
Friends	.31	.35	.37
Children	.34	.02	.23
Relatives	**.40**	.39	.19
Home	**.58**	.36	.33
Neighbourhood	**.66**	.20	.02
Community	**.68**	.16	.02

Note. Bold indicates that item loading on a factor is 0.40 or above.

Highest loadings on Factor 1 were from Community, Neighbourhood, Home, Love, Money, and Relatives. In this rotated solution, Factor 1 accounted for 37% of the variance and may be viewed as a Family and environment factor. The second factor accounted for a further 9% of the variance and described self-actualisation factors including Learning, Creativity, Helping, Play, and Goals & Values. The third factor showed highest loadings for Self-esteem, Health, Play, Work and Goals & Values. This third factor accounted for 7% of the variance and may be thought of as a Self-functioning and activity factor.

A comparison factor structure using only the satisfaction scores from the same sample just examined is provided for comparison in Table 5.5. In this procedure, only the domain satisfaction scores were admitted to the principal axis analysis. Like the previous analysis shown in Table 5.4 three factors had an Eigen value greater than one and accounted for a total of 56% of the variance.

Table 5.5

Factor Structure of the QOLI Relying on Satisfaction Scores Only

Domains	Factors		
	I	II	III
	40% variance (Family & environment)	7% variance (Self actualisation)	9% variance (Self-functioning & activity)
Health	.03	.14	**.61**
Self Esteem	.27	.23	**.66**
Goals &Values	.25	**.50**	**.54**
Money	**.49**	.21	**.40**
Work	.21	.26	**.45**
Play	.23	**.42**	**.57**
Learning	.22	**.79**	.25
Creativity	.34	**.58**	.24
Helping	.18	**.62**	.25
Love	**.47**	.22	.28
Friends	.37	.26	.39
Children	.33	-.03	.22
Relatives	**.49**	.27	.18
Home	**.55**	.27	.38
Neighbourhood	**.64**	.21	.09
Community	**.71**	.22	-.08

Note. Bold indicates that item loading on a factor is 0.40 or above.

In Table 5.5, Factor 1 showed highest loadings from Community, Neighbourhood, Home, Relatives, Money, and Love. Factor 1 accounted for 40% of the variance and may be viewed as a Family and environment factor. The second factor extracted showed highest loadings for Self-esteem, Health, Play, Goals & Values, Work, and Money. This second factor accounted for 9% of the variance and may be thought of as a Self-functioning and activity factor. The third factor accounted for a further 7% of the variance and included Self-actualisation domains such Learning, Helping, Creativity, Goals and values and Play.

There was strikingly little difference between the solutions. The solutions each accounted for 53% to 56% of total variance, with three factors identified. Comparison of these two approaches to identifying the factor structures of the QOLI are provided in Table 5.6. In this table, the only difference between the two factor solutions was the inclusion of Money with a rounded factor loading of .40 in the Self-functioning and activity factor of the analysis using only satisfaction scores.

Table 5.6

Comparison of QOLI Factor Structures

Importance weighted satisfaction domain scores		Satisfaction domain scores only
Factor name	QOLI Domains	QOLI Domains
Family & environment	Community, Neighbourhood, Home, Relatives, Love, Money.	Community, Neighbourhood, Home, Relatives, Love, Money.
Self-actualisation	Learn, Create, Help, Play, Goals and Values.	Learn, Create, Help, Play, Goals and Values
Self-functioning & activity	Self-esteem, Health, Play, Work, Goals & Values.	Self-esteem, Health, Play, Work, Goals & Values, ***Money***.

In addition to these comparisons of factor structure, the distributions of the two approaches to using information gathered by the QOLI were compared. Mean satisfaction scores were calculated using a procedure similar to that used for importance-weighted satisfaction scores. The mean satisfaction score of each domain of the QOLI was calculated for each participant. The distributions are presented in Table 5.7.

Table 5.7

Comparison of QOLI Importance-weighted and Satisfaction Only Domain Scores

	Importance-weighted		Satisfaction only	
	Raw	T-Score	Raw	T-Score
Mean	2.51	50.02	1.53	50.03
Standard Deviation	1.70	10.01	1.01	9.98
75th percentile	3.63	56.59	2.25	57.13
Median	2.75	51.41	1.81	52.80
25th percentile	1.66	45.00	1.00	44.75
Minimum	-3.94	12.07	-2.00	15.05
Maximum	5.88	69.79	3.00	64.55
Skew	-.81	-.81	-1.08	-1.08
Kurtosis	.75	.75	.77	.77

Note. N = 470. Importance-weighted satisfaction raw scores have a possible range of –6.00 to +6.00. Satisfaction only raw scores have a possible range of –3.00 to +3.00.

Table 5.7 shows very small differences in T-scores between the distributions. Comparison of T-Scores across the key points of the distributions show scores to be within three points at the 25th, 50th and 75th percentiles. Skew and kurtosis were also similar. Correlational analysis between total importance-weighted satisfaction and unweighted satisfaction variables showed a very strong relationship, $r = .94$, $p < .001$.

5.6.3 Confirmatory Factor Analysis

The model suggested by the EFA was assessed by a confirmatory factor analysis (CFA), using the second sub-sample of 235 participants and the Analysis of Moment Structures (AMOS) version 6 software package (in SPSS 15). The model was initially assessed and subsequently refined using the resulting standardised regression weights found for each of the observed variables and modification indices. In designing the initial model, circles represent latent variables and rectangles represent measured variables. Independence of error terms was specified and factors were allowed to be correlated. Assumptions of multivariate normality and linearity were evaluated through SPSS and found acceptable. There were no missing data.

Multiple goodness of fit tests were used to evaluate the model (Bentler & Bonnet, 1980). These included the minimum sample discrepancy divided by degrees of freedom, known as relative or normal chi-square (CMIN/DF; Ullman, 2001), the comparative fit index (CFI; Bentler, 1988), the goodness of fit index (GFI; Joreskog & Sorbom, 1993) and the root mean squared error approximation (RMSEA; Browne & Cudeck, 1993). The initial model is shown in standardised form in Figure 5.1.

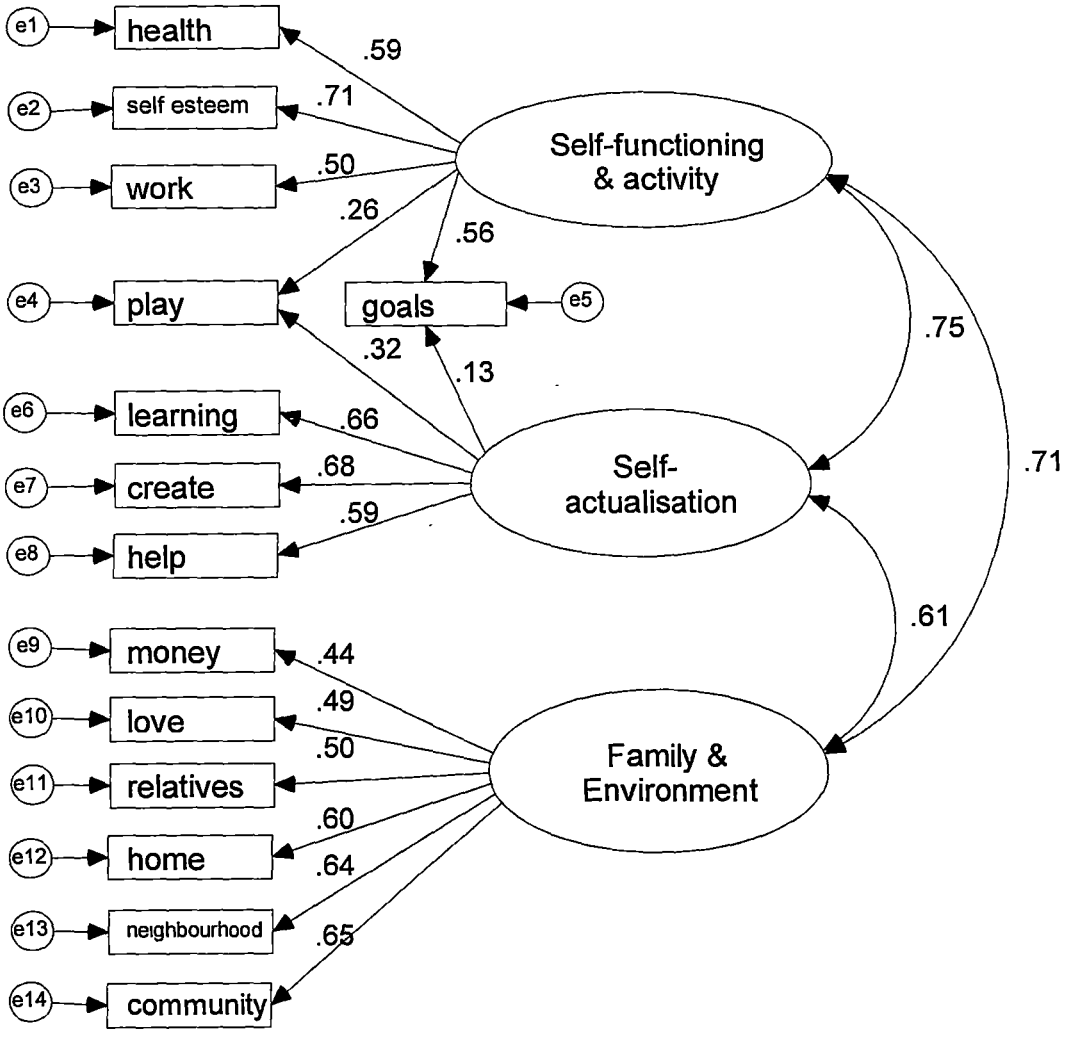


Figure 5.1. Initial model showing standardised regression weights.

Maximum likelihood estimation was employed to estimate all models. The independence model that tests the hypothesis that all variables were uncorrelated was easily rejected, χ^2 (91, N = 235) = 914.37, p <.01. The hypothesized model was tested next using the Chi-square test, χ^2 (72, N = 235) = 181.91, p < .01. Whilst significance can indicate poor model fit, Ullman (2001) explains trivial differences between sample and estimated population covariance

matrices can give inaccurate results. Such problems have necessitated development of a number of Goodness of Fit indices.

Ullman (2001) explains the interpretation of a number of frequently reported indices. Firstly, Normal Chi-square (CMIN/DF) with a value less than 2 is likely to indicate an adequate fit to the data. A Comparative Fit Index (CFI) and Goodness of Fit Index (GFI) greater than 0.90 indicates the model is a good fit to the data. A Root Mean Squared Error Approximation (RMSEA) with values of less than 0.08 indicates a good fit to the data, while values greater than 0.10 suggest strongly that the model fit is unsatisfactory. A statistically significant chi-square can occur as a result of trivial variations in the distribution of data (Ullman, 2001). Goodness of fit tests showed this initial model had potential to fit the data as shown in Table 5.8.

Table 5.8

Initial Goodness of Fit test indices

	CMIN/DF	RMSEA	CFI	NFI	GFI
Fit to data if	<2	<.08	>.9	>.9	>.9
Initial model	2.53	.08	.87	.80	.90

Note. Fit to data indicates thresholds for adequate model fit for each test. Normal chi-square (CMIN/DF), Comparative fit index (CFI), Goodness of fit index (GFI), Root mean squared error approximation (RMSEA).

The modification indices suggested reduction of the Chi-square score by 37.79 if the error terms e13 (on Neighbourhood) and e14 (on Community) were allowed to covary. Given the high correlation between these two variables, this was considered theoretically acceptable.

Also in this initial analysis, the following two pathways had non-significant regression estimates at the .05 level:

- Play and Self-functioning, $p = .06$.
- Goals and Self-actualisation, $p = .36$.

The model was therefore modified to remove these non-significant relationships and allow the specified error terms to covary. On testing this modified model, the Chi-square was significant, χ^2 (73, N = 235) = 135.26, $p < .01$. Support for this modified model was found across the other Goodness of Fit test indices shown in Table 5.9.

Table 5.9

Goodness of Fit test indices for the modified model

	CMIN/DF	RMSEA	CFI	GFI
Fit to data if	<2	<.08	>.9	>.9
Modified model	1.85	.06	.92	.92

Note. Fit to data indicates thresholds for adequate model fit for each test. Normal chi-square (CMIN/DF), Comparative fit index (CFI), Goodness of fit index (GFI), Root mean squared error approximation (RMSEA).

The indices shown in Table 5.9 indicated a sound fit for the data to the modified model across the indices. High inter-correlations (.69 to .83) between the factors were also noted. The final model, in unstandardised and standardised form is shown in Figures 5.2 and 5.3.

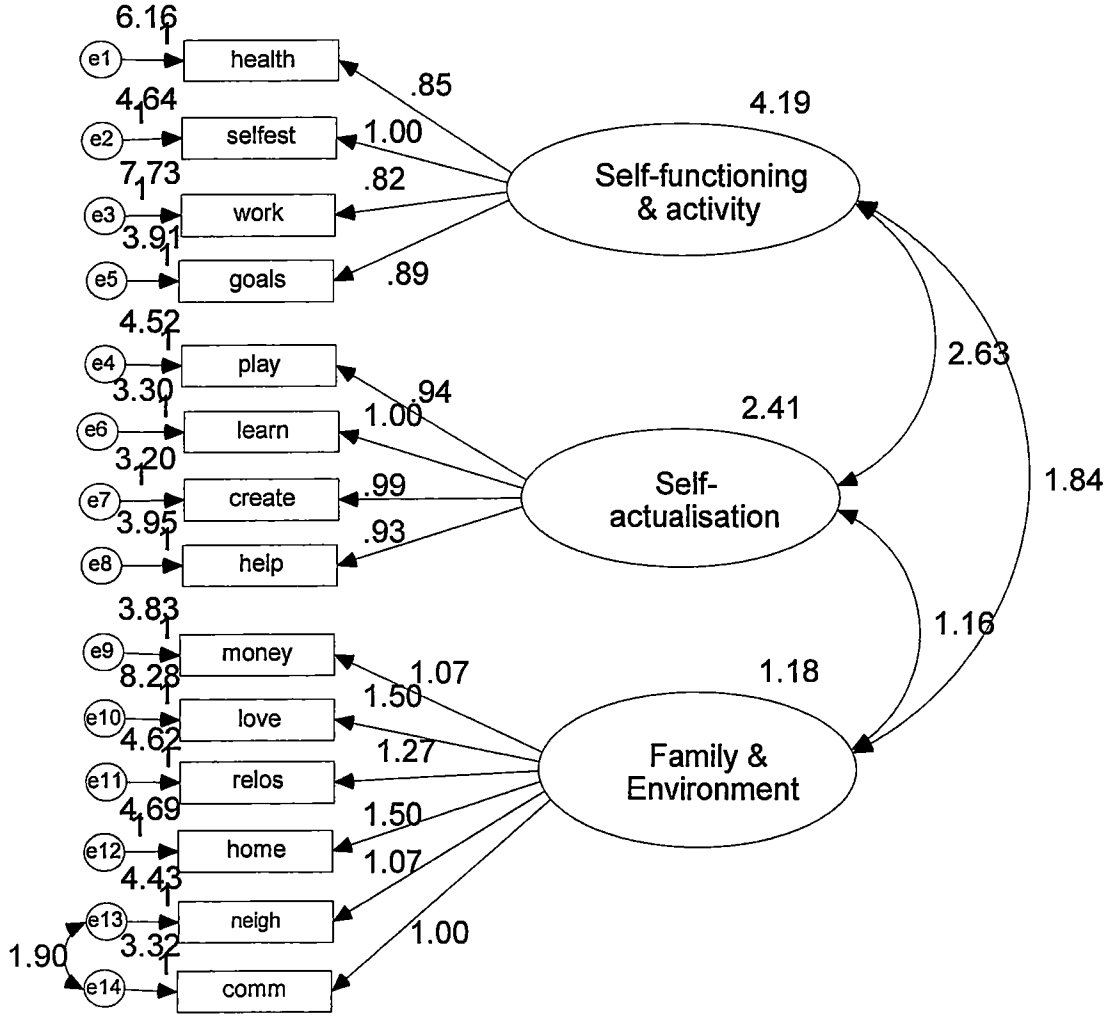


Figure 5.2. Modified model showing unstandardised regression weights.

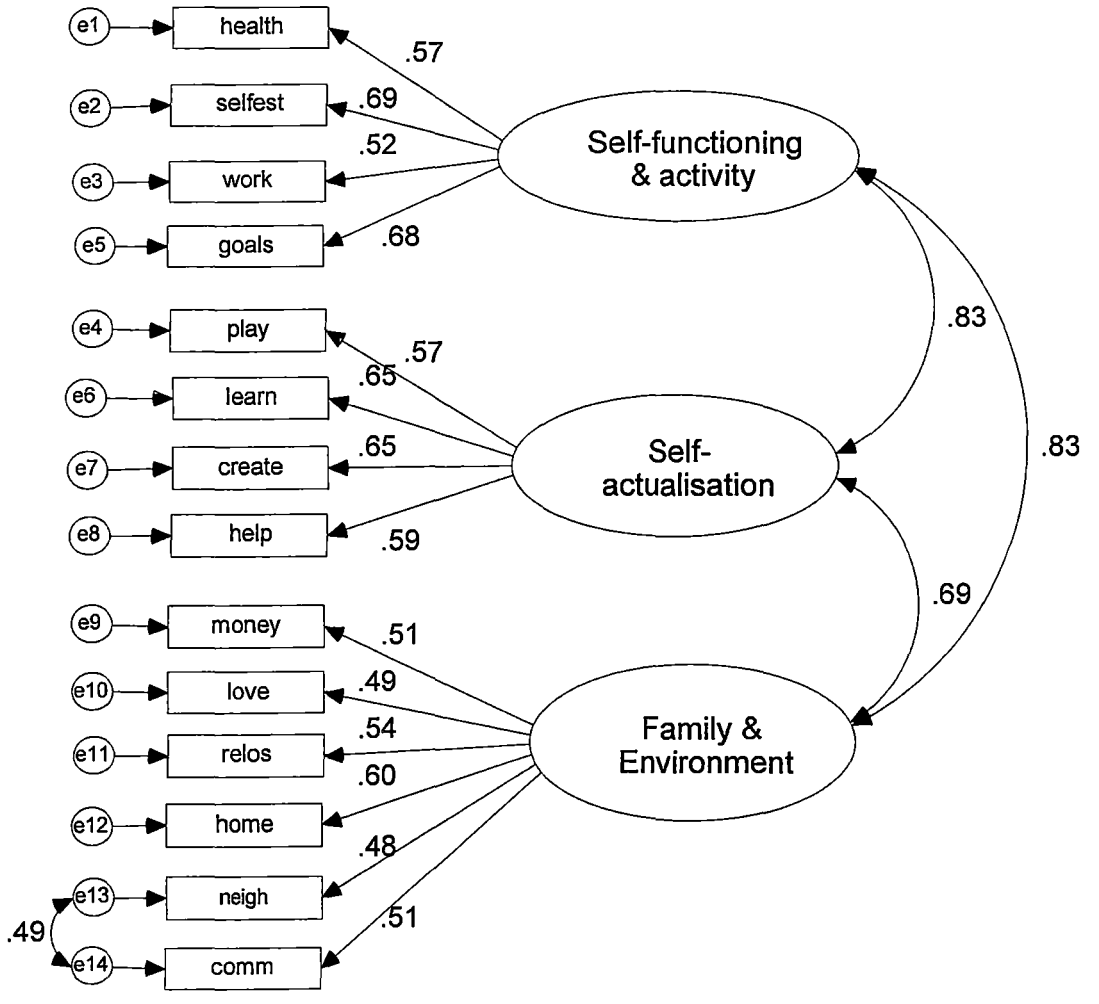


Figure 5.3. Modified model showing standardised regression weights.

5.7 Discussion

The present study sought to compare pre-morbid estimates of the SQOL of people who had recently sustained a TBI in Tasmania, Australia with the generic US-based QOLI norms. This study also examined the factor structure of the domains of the QOLI, providing both exploratory and confirmatory analyses. The suggestion in the literature that the QOLI's importance-weighted satisfaction domain scores may provide misleading indications prompted a comparison between the distributions of both the importance-weighted satisfaction scores

and the satisfaction scores alone. In addition, the factor structures of importance-weighted satisfaction scores and the structure of the QOLI using only the satisfaction scores were compared.

The question raised in Study 1 and suggested in previous research that the pre-injury norms of the TBI population may differ from the general population, was refuted by the results of the present study. The distribution of the local sample generally matched the generic US-based sample, the variance of the Tasmanian sample being only slightly greater than that of the US-based norms.

As described in Chapter 2, the only published study in which the QOLI was used to investigate SQOL within a sample of people with TBI, was conducted by Kalpakjian et al. (2004). In summary, Kalpakjian et al.'s (2004) study relied on a sample of 50 community-dwelling people with severe TBI surveyed approximately five years following injury. Compared with Kalpakjian's (2004) distribution, in which the M = 43.08 and SD = 17.24, the distribution of the Tasmanian TBI sample had a higher mean (M = 49.39) and smaller standard deviation (SD = 13.09). Based on Frisch's (1994) distribution, the mean of Kalpakjian et al.'s (2004) sample was at the 21st percentile, on the border between the Low Range and Average Ranges. In comparison, the Tasmanian sample was well within the Average Range at the 46th percentile of (Frisch, 1994) distribution. Clearly, the pre-injury estimations of the QOLI used in this Tasmanian sample are more closely representative of the population described in the standardisation research provided by Frisch (1994) than the severely injured group surveyed by Kalpakjian et al. (2004), several years following

severe TBI. In the context of previous research findings, these results indicate little difference in SQOL rating prior to injury compared with the general population, and the likelihood of a decrease following injury.

The present study also confirmed the factor structure of the QOLI within this sample of Tasmanians with TBI. The structure of domain scores that were importance-weighted and the satisfaction scores only for each domain were compared. In both analyses, principle axis analysis revealed three factors explaining approximately 55% of the total variance. The basic structure of the QOLI importance-weighted satisfaction domains was almost identical to the structure found using only QOLI satisfaction scores for each domain. Little difference was found between the distributions of the QOLI's importance-weighted satisfaction scores and that using only QOLI domain satisfaction scores.

In investigating the question of the desirability of importance-weighted satisfaction scores, the results of the present study demonstrate almost no difference between distributions and factor structure of the QOLI in this TBI sample. There are strong practical arguments from the SQOL/TBI literature for the use of importance-weighting (Brown et al., 2000; Ferrans & Powers, 1985). For example, it may be very useful in measuring aspects of adjustment to injury. The results of the present study show that importance-rating does not significantly affect the distributions or structure of the QOLI. As such, it is concluded that there is little to be gained by disregarding the importance-weighting of QOLI domain satisfaction scores within this TBI sample. It is possible that variation in importance ratings over time following injury will

provide useful insight into adjustment to injury and remain an important contributor to understanding SQOL outcome. Therefore, importance-ratings of QOLI domains are further examined in longitudinal research reported in Study 3 (Chapter 6).

Some differences were noted between the structure of the QOLI for the Tasmanian TBI sample and the factor structure of the QOLI in the three published studies that have examined other clinical samples. Table 5.10 presents these different structures.

Table 5.10

QOLI factors and domains derived from other clinical populations.

Tasmanian TBI sample (CFA, n=235)	Chronic back pain (EFA, n=253) (Claiborne et al., 1999)	Social anxiety (EFA, n=138) (Eng et al., 2005)	HIV infection (EFA, n=152) (O'Cleirigh & Safren, 2006)
1. **Family & environment:** Relatives, Love, Money, Home, Community, Neighbourhood. 2. **Self-actualisation**: Learning, Creativity, Helping, Play. 3. **Self-functioning & activity:** Health, Self-esteem, Work, Goals & Values.	1. **Family support:** Love, Friends, Children, Relatives. 2. **Environment:** Home, Neighbourhood, Community. 3. **Personal growth:** Learning, Creativity, Helping. 4. **Accomplishment:** Goals & values, Money, Work, and Play. 5. **Health:** Health, Self-esteem.	1. **Social functioning:** Play, Love, Helping, Friends, Relatives. 2. **Surroundings:** Neighbourhood, Community. 3. **Personal growth:** Goals & values, Learning, Creativity 4. **Achievement:** Self-esteem, Money, Work, Home.	1. **Interpersonal relationships:** Relatives, Children, Love, Friends, Helping. 2. **Environment:** Community, Neighbourhood, Home. 3. **Self-expression:** Learning, Creativity, Play. 4. **Achievement:** Self-esteem, Health, Money, Goals & values, Work.

Whilst the number of factors varied between clinical samples, striking similarities were observed across groups in the QOLI factor structures in Table 5.10. The main factors seen in each clinical sample included aspects of Relationships, Environment, Personal growth or Self-actualisation, Self-functioning and Achievement. Aspects of these key factors were clearly evident within the CFA in the present study.

In contrast with the other three clinical groups, it is important to note the factor structure of the Tasmanian TBI sample consisted of pre-injury estimates of SQOL. These estimates were generally obtained within four weeks of the participants' head injury. In contrast to the chronic back pain, social anxiety and HIV positive samples presented in Table 5.10, the structure of the QOLI in a sample of the population before experiencing head injury should not reflect the stress of deficits related to TBI. Rather, it should reflect the normal functioning of a sub-sample of the community that will experience TBI. Given the description of the TBI population by Hillier et al. (1997) and Tate et al.'s (1998) epidemiological studies, it is certain those with TBI have characteristics that are not representative of the general population, such as an over-representation of males of younger mean age and minimum education. This study has indicated these characteristics are not strongly related to SQOL as measured by the QOLI.

5.7.1 Limitations and directions for further research

The present study provided important reference information for the research undertaken within this thesis that will track and ultimately predict SQOL outcome following TBI. By comparing pre-injury estimates of SQOL and

providing a confirmatory examination of the structure of QOLI for a population-based Australian sample of people with TBI, the present research offers an important premorbid reference for future TBI/SQOL investigations.

Unlike Frisch's (1994) QOLI normalisation study, the present study was limited by the sample not being representative of the general population. Rather the Tasmanian TBI sample was generally representative of the TBI population as described in previous Australian epidemiological studies (Hillier et al., 1997; Tate et al., 1998). Whilst no comparison factor structure of the QOLI has been published within a stratified sample of the general Australian population, little difference was found between the US-based normative distribution and pre-injury estimates of Tasmanians with TBI, suggesting this may not be an important direction for future research.

A further limitation included this study's reliance on estimates of pre-injury SQOL functioning prior to TBI by a sample surveyed following injury. It is acknowledged participants' accuracy in estimating their pre-injury SQOL following a traumatic event involving head injury may not be entirely accurate. Whilst the possibility of inaccuracies in this methodological approach is acknowledged, no alternative approaches were available to acquire this information. It was noted there was little difference between the local sample and Frisch's (1994) normative sample.

The small number of participants from this study who had sustained a Severe TBI was also noted. It is likely this was due to the methodology requiring respondents to rate their pre-injury SQOL within 28 days of injury and the very low occurrence of TBI at this extreme. However, the lack of participants with

more severe TBI is a limitation that will be addressed in later studies in this thesis. The relationship of severity of injury to SQOL outcome, as well as other key demographic variables will be investigated in Chapter 8.

In conclusion, this preliminary study found striking similarity between pre-injury estimates of Tasmanians with TBI and Frisch's (1994) normative distribution. In what appears to be the first confirmatory factor analysis reported for the QOLI in any clinical or normal population study, a three-factor solution was confirmed for the QOLI within this Tasmanian sample. This solution bore structural similarities to exploratory analyses in other clinical populations. Comparison of factor analysis results suggested importance-weighting of satisfaction scores produced negligible differences in factor solution and distribution of scores compared with using only satisfaction scores across the QOLI domains. As it may be likely that importance-weighting provides useful insights into aspects of adjustment to injury over time following injury, this will be further investigated in the next study. The next study examines longitudinal SQOL outcome following TBI.

CHAPTER 6

STUDY 3 - LONGITUDINAL SUBJECTIVE QUALITY OF LIFE OUTCOMES FOLLOWING TRAUMATIC BRAIN INJURY

The methodology and results of Study 3 are presented in this chapter. Study 3 reports the SQOL ratings on the Quality of Life Inventory (QOLI, Frisch, 1994) of adults with TBI at several time points over the course of twelve months following their injuries. Following on from Study 2, the present research was conducted to further validate the QOLI and establish reference information for its use within the TBI population. The present study is a necessary precursor to research reported in this thesis, which ultimately seeks to develop predictive models of SQOL outcome following TBI.

6.1 Aims

Study 3 aimed to provide the trend and normative distribution of the QOLI Total and Factor scores for a sample of adults following TBI, at one, three, six and twelve months following injury. A comparison of mean importance-weighted satisfaction, mean satisfaction-only scores, and mean importance-rating scores aimed to determine the usefulness of importance-weighting of SQOL domains, over time following injury, within this population. Study 3 also sought to examine the relationships of the QOLI Total and Factor scores over time following injury.

6.2 Design

This study utilized a cross-sectional and longitudinal design with a sample of people who had sustained a TBI. The cross-sectional data collection occurred with a population-based sample of participants at four time points (one, three, six and twelve months) following their head injury. A pre-injury estimate of

functioning was collected as soon as possible following injury. Outcomes were examined separately for participants returning data at each time point and those returning data at adjacent time-points (e.g., one month and three months, three months and six months). A number of participants provided data at all time points and joined a longitudinal cohort.

6.3 Participants

As in Study 2, participants in the present study were adult volunteers who had recently sustained a TBI and consented to involvement in the TBI Outcome Study operated by the Neurotrauma Register of Tasmania (NTR, Slatyer & Thomas, 2005). Characteristics of the participants in the cross-sectional and longitudinal analyses were very similar to those found in Study 2 (in Chapter 5). In the cross-sectional sample 64% were male, a slightly lower proportion than the longitudinal cohort (69%). Table 6.1 shows other demographic features.

Table 6.1

Demographic characteristics of the cross-sectional and longitudinal samples

	Cross-sectional sample $N = 663$				Longitudinal sample $N = 51$			
	M	*SD*	*Mdn*	*Range*	*M*	*SD*	*Mdn*	*Range*
Age (years)	35.45	17.18	30.94	16 to 91	33.27	15.99	27.44	16 to 76
Education (years)	11.10	2.41	10.00	0 to 26	12.00	2.24	11.00	10 to 18
Estimated IQ	96.71	11.30	97.00	69 to 121	95.88	12.24	95.00	73 to 121

Table 6.1 shows the longitudinal sample was slightly younger, and also had a slightly higher and narrower range number of years of education than the cross-sectional sample. Table 6.2 compares the causes of injury for the two samples.

Table 6.2

Comparison of the proportion of causes of injury

Cause	Cross-sectional *N* = 663	Longitudinal *N* = 51
	%	%
Transport	39	44
Assault	29	24
Fall	19	16
Sport	8	10
Other	5	6

Similar proportions of causes of injury were observed between cross-sectional and longitudinal samples. The proportions of participants in each category of severity of injury were also similar, as shown in Table 6.3.

Table 6.3

Severity of traumatic brain injury within the cross-sectional and longitudinal samples (Russell, 1977)

Severity	Duration of PTA	Cross-sectional Sample		Longitudinal Sample	
		n	%	n	%
Very Mild	<= 5 minutes	142	22	13	26
Mild	5+ to 60 minutes	145	23	16	32
Moderate	1+ to 24 hours	164	26	10	20
Severe	1+ to 7 days	125	20	10	20
Very severe	1+ to 4 weeks	55	8	1	2
Extremely severe	> 4 weeks	8	1	0	0

Table 6.3 shows most participants sustained a mild TBI with a much smaller percentage of the group suffering moderate or severe TBI.

6.4 Measures

The Quality of Life Inventory (QOLI, Frisch, 1994) was used to provide indications of participants' SQOL. A detailed description of the QOLI and its psychometric properties is provided in Chapter 2 of this thesis.

6.5 Procedure

Patients notified to the NTR TBI Outcome Study were interviewed as soon as possible following injury to determine their eligibility and to gain their consent. Eligible and consenting participants initially completed the Mini-Mental State Examination (MMSE, Folstein et al., 1975), and if scoring 23 or greater,

then completed a battery comprising neuropsychological tests, and questionnaires asking for medical as well as demographic information.

As part of this battery, participants completed the QOLI at approximately one month, three months, six months and twelve months following TBI. Participants' QOLI importance-weighted raw scores were calculated and compared with the normative QOLI distribution (Frisch, 1994). QOLI outcome for the cross-sectional and longitudinal samples were examined separately. QOLI importance and satisfaction scores were also examined separately. QOLI factor scores were also examined over the time-points following injury. Relationships between the QOLI Total and factor scores were examined using correlational analysis.

QOLI Total scores and factor scores were calculated using standard methods (Frisch, 1994; Tabachnick & Fidell, 2001). QOLI Total scores were calculated according to the QOLI Manual (Frisch, 1994), and were the product of importance ratings (possible range of 0, 1 or 2) and satisfaction ratings (possible range of -3 to +3), providing a total possible range of -6 to +6. The three factor scores were calculated based on the confirmatory factor structure provided in Chapter 5. Each of the QOLI Factors was treated as a subscale of the QOLI. Unit-weighted composite scores were calculated for each subscale (Thompson, 2004). Tabachnick & Fidell (2001) describe this approach to scoring subscales from the factor structure of an instrument as statistically adequate (p.626).

The procedure for scoring each subscale assumed QOLI domain scores were each equally weighted on the QOLI subscales. QOLI subscales were calculated by summing the relevant QOLI domains found to load onto the

subscale, and then dividing by the number of items that loaded onto that subscale This yielded a QOLI Factor or subscale score with a possible range of -6 to +6, which made clinical interpretation straightforward, as the possible range of QOLI Factor scores was the same as the QOLI Total score. There are many examples of studies that have employed this procedure (e.g., Cheung, 2002; Varni, Seid, & Kurtin, 2001). An alternative approach to calculating QOLI Factor scores involving scaling of QOLI Factor scores to a T- distribution (M = 50, SD = 10) was considered. However, it was felt unit-weighted composite scores provided a statistically adequate method that preserved the clinical meaning of scores at item level. They were therefore employed to best address the aims of the present clinically oriented TBI outcome research. The complete output of these analyses is presented in the Chapter 6 folder on the Appendix CD.

6.6 Results

The results of this study are presented in four sections.

1. The QOLI (mean importance-weighted satisfaction) distributions across the four time-points following TBI for the Tasmanian sample are presented and compared with the generic US-based normative distribution and the pre-injury estimate of SQOL within this Tasmanian sample. In addition, trends in importance and satisfaction ratings of the QOLI domains are compared separately.

2. The longitudinal QOLI outcome for the cohort returning data at all time-points following TBI is compared with the cross-sectional outcome data.

3. The distributions of the three QOLI factor scores, identified in Study 2 (in Chapter 5) are examined. Separate comparisons of importance-weighted satisfaction factor scores, with importance-only scores and satisfaction-only scores for each of the QOLI factors are also presented.

4. The relationships of the QOLI Total scores and factor scores are examined using correlational analysis.

6.6.1 QOLI distributions over time following TBI

Table 6.4 compares the raw scores of cross sectional samples of Tasmanians with TBI, across the four time-points of the study with Frisch's (1994) generic US-based distribution and the pre-injury estimate of SQOL provided by the Tasmanian TBI sample. As already described in the previous study (Study 2), there was little difference between the Tasmanian TBI distribution at the pre-injury time-point and Frisch's (1994) normative sample. However, over the time-points there was a decrease in the Tasmanian samples mean scores compared with Frisch's normative sample.

Table 6.4

Cross-sectional QOLI Raw Score Distributions of the Tasmanian TBI Sample Compared with the Generic US-Sample

	Tasmanian TBI sample					Frisch (1994)
Statistic	Pre-injury (n = 470)	1 Month (n = 315)	3 Months (n = 293)	6 Months (n = 226)	12 Months (n = 202)	US-based (n = 798)
Mean	2.52	2.15	2.18	2.30	2.37	2.60
Standard Deviation	1.70	1.95	1.94	1.68	1.68	1.30
Percentile of the mean[a]	46	36	36	39	42	49
75th percentile	3.63	3.56	3.62	3.53	3.40	5.70
Median	2.75	2.47	2.38	2.61	2.58	2.65
25th percentile	1.66	1.06	1.21	1.27	1.32	1.83
Skew	-.81	-.72	-.92	-.67	-.76	NA

Note. a. Based on Frisch's (1994) distribution. Information is not available (NA).

Compared with the pre-injury estimate, mean and median scores were seen to fall at the one and three-month data collection points. The mean score at the six-month data point was slightly higher than at three-months, as was the twelve-month mean slightly higher than the six-month mean. This trend is seen in the percentile of the mean across these time-points. Compared with Frisch's distribution, the percentile of the mean was observed to decrease to the 36th percentile at the one-month and three month time-points, then rise to the 39th percentile at six-months, and the 42nd percentile twelve months following injury.

Statistically significant differences were found between Frisch's (1994) mean of 2.60 and the Tasmanian TBI distributions. The results of one-sample T-tests are shown in Table 6.5.

Table 6.5

Comparisons of Frisch's (1994) QOLI distribution with the TBI Sample

Time-point	*t*	*df*	*p*
Pre-injury	-1.07	465	.28
1 Month	-4.07	314	***.001***
3 Months	-3.69	292	***.001***
6 Months	-2.67	225	***.01***
12 Months	-1.99	201	.05

Note. t-score (*t*), degrees of freedom (*df*), two-tailed significance (*p*).

Table 6.5 shows no significant difference between distributions at the pre-injury time-point, but significantly lower scores at one, three and six months following injury, compared with Frisch's distribution.

To examine differences within the Tasmanian TBI sample, paired t-tests were used to compare the pre-injury estimate with distributions at the data points following injury. Compared with the pre-injury estimates, significantly lower QOLI ratings were observed at one month and three months following injury. T-test results are shown in Table 6.6.

Table 6.6

T-test Comparisons of the Pre-injury Estimates of the Tasmanian TBI Sample with Distributions at Time-points Following TBI

Time-point	*t*	*df*	*p*
1 Month	3.84	217	***.001***
3 Months	2.05	168	***.04***
6 Months	1.44	123	.15
12 Months	-.68	105	.50

Note. t-score (*t*), degrees of freedom (*df*) two-tailed significance (*p*).

An examination of participants' mean importance scores and satisfaction scores across the domains of the QOLI was undertaken, to find the trends in these component scores for each data-point of the study. Table 6.7 and 6.8 show the QOLI importance and satisfaction scores respectively.

Table 6.7 below, shows very little change in mean total importance scores over the time-points of the study (Importance scores range 0 = Not important, 1 = Important, 2 = Extremely important). No statistically significant differences were found between the pre-injury estimate and other time points.

Additionally, examination of participants' mean total satisfaction scores in Table 6.8 showed a similar pattern to the QOLI Total scores across the time-points. Paired-sample t-tests showed two statistically significant differences between the pre-injury estimates and data-points. These were between the pre-injury estimates and one-month scores t (217) = 3.79, $p < .01$, and three month scores t (168) = 2.08, $p < .05$. The difference between pre-injury estimates and six months scores approached significance t (123) = 1.73, $p = .09$.

Table 6.7

QOLI Importance Distributions of the Tasmanian TBI Sample

Statistic	Pre-injury (n = 464)	1 Month (n = 319)	3 Months (n = 294)	6 Months (n = 228)	12 Months (n = 203)
Mean	1.34	1.37	1.34	1.32	1.31
Standard Deviation	.31	.30	.31	.31	.32
75^{th} percentile	1.56	1.62	1.56	1.56	1.56
Median	1.38	1.38	1.38	1.31	1.31
25^{th} percentile	1.13	1.13	1.13	1.13	1.06
Skew	-.29	-.02	-.14	-.33	-.31

Table 6.8

QOLI Satisfaction Distributions of the Tasmanian TBI Sample

Statistic	Pre-injury (n = 463)	1 Month (n = 315)	3 Months (n = 291)	6 Months (n = 226)	12 Months (n = 202)
Mean	1.53	1.29	1.37	1.40	1.49
Standard Deviation	1.01	1.15	1.12	1.04	.99
75th percentile	2.25	2.13	2.25	2.25	2.19
Median	1.81	1.63	1.5	1.63	1.69
25th percentile	1.00	.63	.81	.81	.86
Skew	-1.08	-.96	-1.10	-.86	-.99

6.6.2 QOLI outcome for adjacent samples

Comparison was made with the QOLI scores of participants returning data at adjacent time-points.

Table 6.9

Comparison of QOLI Total scores for the adjacent time-point samples.

Time-point	*n*	*M*	*SD*
Pre-injury	218	2.57	1.66
1 Month	218	2.19	1.96
1 Month	184	2.23	1.86
3 Months	184	2.35	1.94
3 Months	154	2.23	1.77
6 Months	154	2.34	1.66
6 Months	147	2.29	1.73
12 Months	147	2.36	1.68

Table 6.9 shows a similar pattern of decrease in scores across the time-points as the cross-sectional outcome data shown in Table 6.4. Paired sample t-tests showed significant differences between pre-injury and one-month, t (217) = 3.84, $p < .01$. In addition, differences were observed between pre-injury and

three month time-points, t (168) = 2.05, p < .05, and three months and twelve months, t (138) = -2.23, p < .05.

This analysis highlighted the issue of possible differences between participants attending early time-points and not returning data at later time-points of the study. Independent samples t-tests compared QOLI scores for participants who returned surveys at both adjacent time-points (e.g. Pre-injury and 1 Month, 1 Month and 3 Months etc) and those participants who returned data at only the first of the adjacent time-points (e.g. Pre-injury but not 1 Month, 1Month but not 3 Months etc). No significant differences were found on QOLI Total scores between participants returning data at both adjacent time-points and those who attended only the first time-point across the data points of the study.

6.6.3 *Longitudinal QOLI outcome*

The distributions of the cohort who returned QOLI surveys at all the time-points of the study were compared with the US-based distribution provided by Frisch (1994) are shown in Table 6.10.

Table 6.10

Longitudinal QOLI raw score distributions of the Tasmanian TBI sample compared with the US-based Sample

	Tasmanian TBI sample (N = 51)					Frisch (1994) (N = 798)
Statistic	Pre-injury	1 Month	3 Months	6 Months	12 Months	US-based
Mean	2.46	2.36	2.21	2.30	2.50	2.60
Standard Deviation	1.54	1.84	2.04	1.91	1.52	1.30
Percentile of the mean	46	42	36	39	46	50.00
75th percentile	3.63	3.50	3.44	3.46	3.13	3.40
Median	2.44	2.47	2.40	2.31	2.73	2.65
25th percentile	1.47	1.21	1.50	1.47	1.75	1.75
Skew	-.43	-.53	-1.32	-.59	-.42	NA

Note. NA = Information is not available

6.6.4 QOLI factor outcomes

The raw distributions for each of the QOLI (importance-weighted satisfaction) factor scores across the time-points of the study are shown in Figure 6.1.

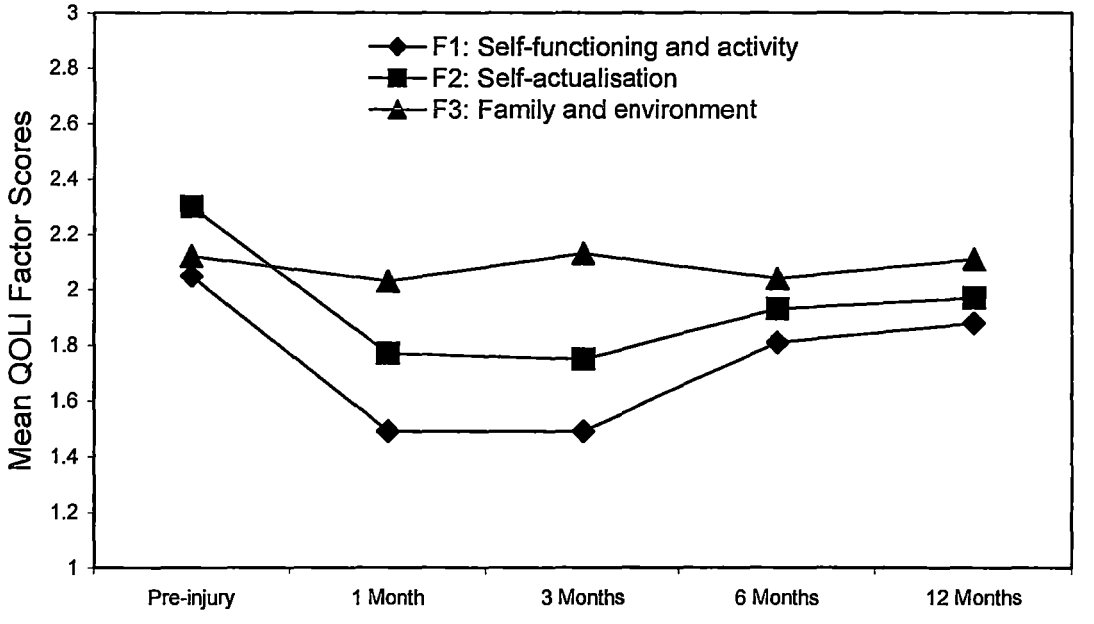


Figure 6.1. Mean QOLI factor scores (Importance-weighted Satisfaction).

Compared with the mean pre-injury factor scores, means for Factors 1: Self-functioning and activity, and Factor 2: Self-actualisation were seen to reduce at the one and three-month post-injury time-points, before returning close to their pre-injury levels at the 12-month time-point. This was similar to the pattern seen for the QOLI Total score, already described in Table 6.4. The trends in Factor 3: Family and environment varied from this general pattern, remaining close to the pre-injury level over the subsequent time-points.

The importance-weighted satisfaction of 'Self-actualisation' was rated highest at the pre-injury estimate. 'Self-functioning and activity' and 'Family and environment' shared similar pre-injury rating levels. Statistically significant

differences on paired sample t-tests between factor scores at the pre-injury estimate and subsequent time-points were noted for two factors. These differences were observed between the pre-injury estimate and one-month data on 'Self-functioning and activity', t (222) = 3.05, $p < .01$, and 'Self-actualisation' t (224) = 3.88, $p < .01$. Significant differences were also observed between the pre-injury estimates and three-month data on these same factors (Factor 1, t (176) = 1.91, $p = .06$, and Factor 2, t (175) = 2.24, $p < .05$). This indicates the mean ratings for Factors 1 and 2 remained lower than pre-injury estimates at both one and three-month time-points before recovery to near pre-injury levels at six and twelve months following injury. Adjacent time-point comparisons were analysed with paired samples t-tests. Significant decreases were only observed between pre-injury estimates and one-month time-points as shown in Chapter 6 Appendix Table 6.1 on the Appendix CD.

Importance-weighted satisfaction scores on 'Self-functioning and environment' and 'Family and environment' were seen to cross over each other between the pre-injury and one-month data-points, indicating relative shifts in importance and satisfaction ratings. Separate examination of the importance and satisfaction scores over the time-points of this study provide further information about the relative importance of each factor, as well as the pattern of scores in satisfaction. Figure 6.2 shows the pattern of scores in importance ratings.

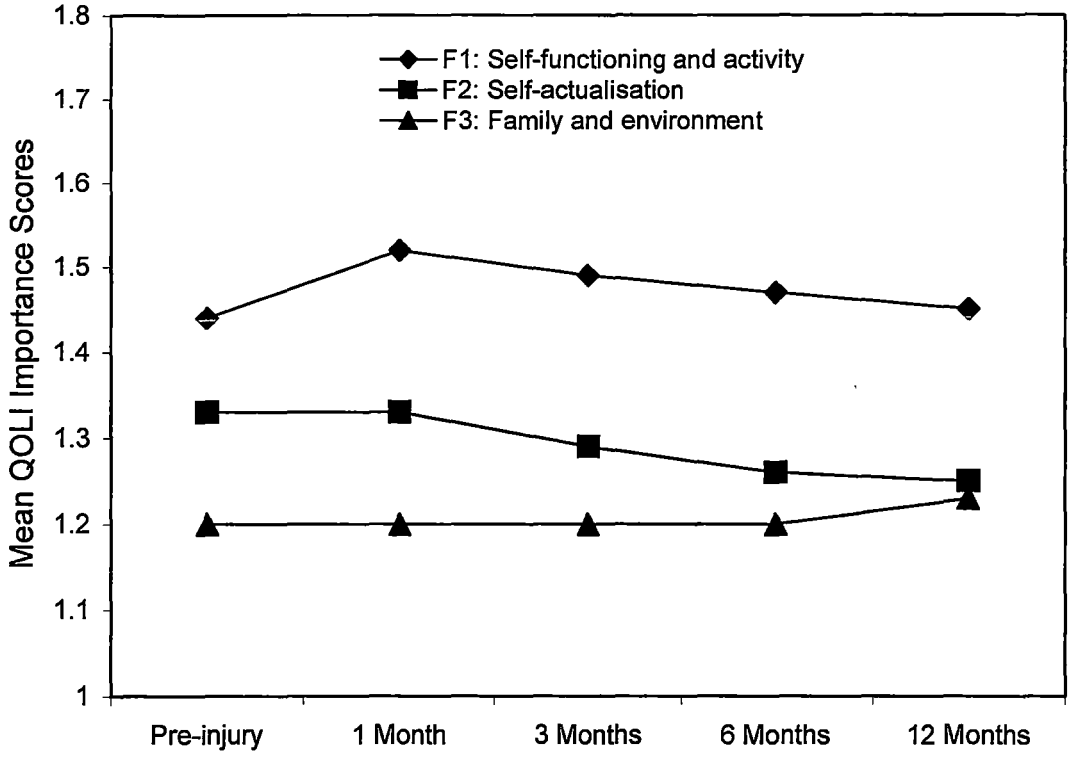


Figure 6.2. Mean QOLI factor importance ratings

Figure 6.2 shows pattern of scores in mean factor importance scores across the time-points following TBI. A significant increase was observed in 'Self-functioning' scores, between the pre-injury estimate and the one-month data-point, t (223) = -2.27, $p < .05$. Importance ratings for 'Self-actualisation' were seen to decrease slightly over the data-points. 'Family and environment' scores were generally stable over the time-points. Adjacent time-point comparisons were analysed with paired samples t-tests. Significant increases were only observed between pre-injury estimates and one-month time-points on 'Self-functioning' between pre-injury and one-month as well as one-month and three-month time-points as shown in Chapter 6 Appendix Table 6.1 on the Appendix CD.

Interestingly, at the pre-injury estimate point, these QOLI factors may be ranked in order of importance, as follows:

1. Factor 1: Self-functioning and activity
2. Factor 2: Self-actualisation
3. Factor 3: Family and environment

Figure 6.3 below shows mean factor satisfaction scores across the time-points of the study.

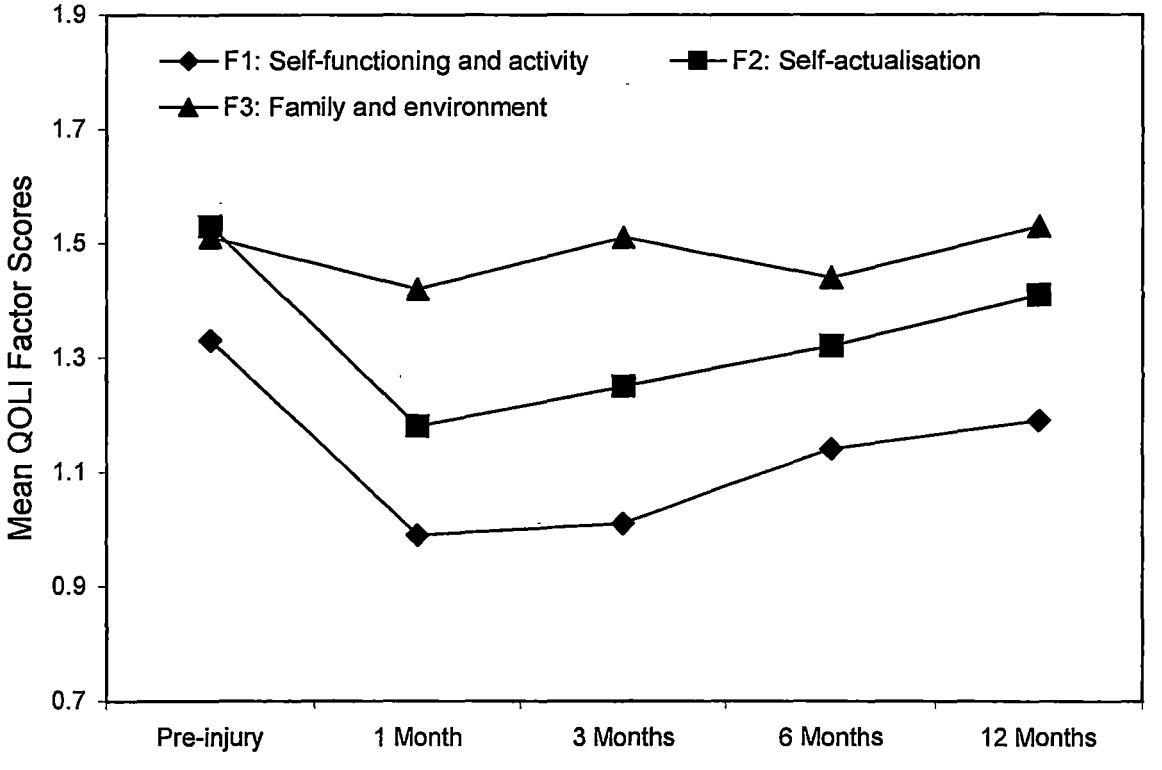


Figure 6.3. Mean QOLI Factor Satisfaction Scores

Figure 6.3 shows the pre-injury estimates of satisfaction of 'Self-actualisation' and 'Family and environment' were rated at approximately the same level. Mean scores for 'Self-functioning and activity' and 'Self-actualisation' were significantly decreased at the one-month data point compared with the pre-injury

estimate (Factor 1, t (222) = 4.34, $p < .01$, and Factor 2, t (224) = 3.37, $p < .01$). Factor 1: Self-functioning and activity remained significantly lower than the pre-injury estimate three-months following injury t (176) = 2.92, $p > .01$. The means of these factors returned to near pre-injury levels at the twelve-month points. Satisfaction levels for 'Family and environment' remained relatively constant across the time-points. Significant decreases were observed for 'Self-functioning' between pre-injury estimates and one-month time-points and 'Self-actualisation' between pre-injury and one-month and then a significant increase between one-month and three-month time-points, as shown in Chapter 6 Appendix Table 6.1 on the Appendix CD.

As with factor importance ratings, it is possible to rank the factors in order from most to least rated satisfaction by the sample at the pre-injury data-point, as follows:

1. Factor 2: Self-actualisation
2. Factor 3: Family and environment
3. Factor 1: Self-functioning and activity

6.6.5 QOLI Total score and factor relationships

In examining the internal relationships of the QOLI across the time-points of the study, the interrelationships between QOLI Total scores were first examined. Next, the relationships between QOLI Total scores and Factor scores across the data-points were investigated. Finally, interrelationships between the QOLI Factor scores were explored across the time-points of the study. Table 6.11 shows the inter-correlations between QOLI Total scores across the time-

points of the study. As there were many correlations, $p < .01$ was adopted as the significance level in the following analysis.

Table 6.11

Relationships of QOLI Total scores over time following TBI

	Pre-injury	1 Month	3 Months	6 Months
1 Month	.69*	-	-	-
3 Months	.53*	.61*	-	-
6 Months	.52*	.61*	.66*	-
12 Months	.47*	.49*	.60*	.66*

Note. * p<.01.

In general, the strongest relationships were observed between variables in serial order, such as Pre-injury QOLI Total score and one-month QOLI Total score ($r = .69$, $p < .001$). Interestingly, the relationship between the three-month QOLI Total score and the twelve-month QOLI Total score was as strong as the six-month QOLI Total score and twelve-month Total QOLI Score.

Table 6.12 below, provides correlation coefficients for QOLI Total and Factor scores across the time-points of the study. Consistently strong relationships were observed between QOLI Total scores and QOLI Factor scores at corresponding time-points. Correlation coefficients with QOLI Total scores across the factors averaged greater than .80 at each time-point. The strength of relationships decreased with increased temporal distance.

Table 6.12

Correlation coefficients of the QOLI Total and Factor Scores Across Data Collection Points

QOLI Total Scores	Pre-injury			1 Month			3 Months			6 Months			12 Months		
	F1	F2	F3	F1	F2	F3	F1	F2	F3	F1	F2	F3	F1	F2	F3
Pre	.83*	.81*	.83*	.57*	.53*	.69*	.51*	.44*	.49*	.45*	.41*	.51*	.30*	.36*	.49*
1M	.55*	.53*	.64*	.88*	.87*	.83*	.56*	.57*	.52*	.51*	.59*	.55*	.28*	.37*	.39*
3M	.35*	.35*	.57*	.54*	.50*	.52*	.86*	.86*	.83*	.53*	.54*	.56*	.43*	.59*	.50*
6M	.37*	.40*	.42*	.54*	.50*	.51*	.60*	.55*	.58*	.85*	.82*	.83*	.49*	.47*	.59*
12M	.24*	.39*	.41*	.42*	.39*	.44*	.58*	.54*	.51*	.55*	.54*	.58*	.79*	.86*	.82*

Note. * p<.01.

Table 6.13 below, shows a number of interesting patterns in the inter-relationships between the factor scores over the data-points following TBI. Firstly, it is clear that each factor score was most highly correlated with itself. For example, Factor 1 scores correlated most highly with Factor 1 scores across the time-points, and this holds for all the relationships between factors. Moderate to high correlations were observed for corresponding factors at neighbouring time points. Also, in looking at relationships between the factors over time following injury, the relationship of pre-injury factors are strongest with data one month following injury and progressively weaken across the three, six and twelve month data-points.

Table 6.13

Correlation coefficients of the QOLI Factor Scores across data collection points

Variables	Pre-injury			1 Month			3 Months			6 Months		
	F1	F2	F3	F1	F2	F3	F1	F2	F3	F1	F2	F3
1 Month												
Factor 1	.56*	.45*	.49*	-	-	-	-	-	-	-	-	-
Factor 2	.43*	.52*	.43*	-	-	-	-	-	-	-	-	-
Factor 3	.47*	.50*	.76*	-	-	-	-	-	-	-	-	-
3 Month												
Factor 1	.39*	.33*	.49*	.57*	.50*	.44*	-	-	-	-	-	-
Factor 2	.29*	.38*	.41*	.50*	.55*	.44*	-	-	-	-	-	-
Factor 3	.28*	.30*	.64*	.36*	.34*	.60*	-	-	-	-	-	-

Note. *p<.01.

Table 6.13 (continued)

Correlation coefficients of the QOLI Factor Scores across data collection points

Variables	Pre-injury			1 Month			3 Months			6 Months		
	F1	F2	F3	F1	F2	F3	F1	F2	F3	F1	F2	F3
6 Month												
Factor 1	.43*	.39*	.27*	.48*	.40*	.36*	.57*	.44*	.43*	-	-	-
Factor 2	.29*	.43*	.25*	.56*	.62*	.44*	.49*	.60*	.44	-	-	-
Factor 3	.29*	.38*	.59*	.43*	.45*	62*	.47*	.41*	.65*	-	-	-
12 Month												
Factor 1	.25*	.26*	.17	.41*	.29*	.15	.55*	.41*	.26*	.49*	.44*	.38*
Factor 2	.14	.39*	.31*	.33*	.34*	.34*	.55*	.56*	.50*	.41*	.47*	.40*
Factor 3	.18	.38*	.54*	.23*	.25*	.51*	.39*	.43*	.53*	.42*	.44*	.69*

Note. *p<.01.

6.7 Discussion

The aims of Study 3 were to provide the pattern of scores and normative distribution of both the QOLI Total and Factor scores for a sample of adults following TBI, across time-points to twelve months following injury. This study also sought to examine mean importance-weighted satisfaction (QOLI Total score), mean satisfaction, and importance-rating scores separately, to determine the contribution of importance ratings in describing SQOL over time following TBI. In addition, an examination of the inter-relationships of the QOLI Total and Factor scores over time following injury was undertaken.

Compared with the mean of Frisch's (1994) normative sample, the cross-sectional analysis of the present study found little difference between QOLI Total scores at the pre-injury time point. This was expected following the results of Study 2. In response to TBI expert consensus group calls for investigation of the validity of normative information provided with SQOL instruments within the TBI population (e.g., Bullinger, 2002; NIH, 1999), the present study has determined the US-based normative distribution provided with the QOLI (Frisch, 1994) can be applied with confidence within the local TBI rehabilitation and outcomes research context. The present study extends the results of Study 2 by providing longitudinal outcome data.

Across the cross-sectional samples, significantly lower QOLI Total scores were rated at the one, three and six-month time-points post injury, compared with Frisch's (1994) normative distribution (shown in Table 6.4). Compared with the Tasmanian pre-injury estimates, significant reductions in SQOL rating were noted at one and three-month time-points post injury (shown in Table 6.6). This

pattern in the QOLI Total score suggests there is a reduction in satisfaction and/or increase in importance ratings across QOLI domains following injury. The longitudinal samples showed a non-significant reduction in QOLI Total scores at the one, three and six-month time-points, before regaining the pre-injury level, at the twelve month time-point. Reasons for similar but non-significant pattern of scores may be related to the relatively small size of the longitudinal sample compared with the cross-sectional sample. Further discussion of this limitation to the present study is presented later in this discussion.

Examination of the separate pattern of scores in total importance and satisfaction ratings over time showed total mean importance scores remained generally stable over the data-points. Whereas, the satisfaction ratings followed a pattern similar to the QOLI Total score. That is, reductions in scores at the one and three-month data-points and return to near pre-injury levels at the six and twelve-month points. Examination of the QOLI Factors demonstrated the separate contributions of the domains of the QOLI following TBI.

Two of the QOLI Factor scores followed the trend of the QOLI Total score. Factor 1: Self-functioning and activity, and Factor 2: Self-actualisation, were rated lower at the one and three-month time-points. However, Factor 3: Family and environment remained stable over time following TBI. These differences highlighted the usefulness of a factor structure for the QOLI in this population when tracking outcome, as the mean scores of the six domains loading onto this family relationships and environment factor were apparently not affected in ways that were similar to those domains that contributed to the self-functioning and self-actualisation factors. It may be that domains contributing to

this third factor such as relationships with spouse and family, as well as home and community had aspects that were external to the respondent's perceived level of functioning. This is in contrast to domains that are more internal or dependent on the participant's perception of their functioning, such as health, self-esteem, work, creativity and helping others, which are aspects of cognitive and psychosocial functioning that are known to be affected by TBI (Ponsford et al., 1996). It may be that these more internal domains are most vulnerable to impairment and problems arising with participation in vocational roles following TBI, as they are almost solely dependent on the participant engaging in activity that would lead to satisfaction. In considering the main components causing the reduction in SQOL as measured by the QOLI Total scores, it appeared that the trends in satisfaction scores for these factors (Factors 1 and 2) were at the heart of the reduction in QOLI Total scores at one and three-months post-injury.

Separate examination of factor importance and satisfaction scores elucidated this trend in SQOL rating following TBI. Mean importance ratings for Factor 3: Family and environment scores remained relatively stable across time-points, indicating the constancy of importance of QOLI domains in this factor. Factor 2: Self-actualisation importance scores were observed to reduce slightly over time, possibly indicating a reduction in respondents' focus on these domains in the period following injury. These 'Self-actualisation' domains may be viewed as optional or extra areas of life participants may engage in when other more critical aspects such as health and work activity are satisfactory. In addition, this reduction in importance ratings may indicate a process of adjustment whereby participants transfer the importance they place on certain

domains of SQOL that are more critical following injury in which they are not able to achieve acceptable levels of satisfaction. This is observed in the increase in scores on Factor 1: Self-functioning and activity at one-month following TBI (shown in Figure 6.2), indicating respondents rated greater importance on key aspects of self-functioning at the one-month time-point following injury. This increase in importance rating for Factor 1 is multiplied by satisfaction ratings, which when examined separately (in Figure 6.3) generally matched the QOLI Total score trend (provided in Figure 6.1) with reductions at one and three-months for Factor 1 and 2, to produce the significantly reduced QOLI Total scores.

The literature review provided in Chapter 2 summarised the controversy about the inclusion of importance ratings in SQOL measures. Many TBI researchers have indicated the value of importance ratings in providing a facility for respondents to differentiate between domains of their SQOL (e.g., Bullinger, 2002; Dijkers, 2004; Kalpakjian et al., 2004). However, other SQOL researchers have opposed the inclusion of importance ratings stating they do not add any value to satisfaction scores, can artificially inflate satisfaction scores and are therefore redundant and unnecessary (e.g., Cummins et al., 1994; Trauer & Mackinnon, 2001).

The present study shows that within this representative sample of the local TBI population, the relative importance of Factor 1: Self-functioning and activity increased significantly at the one-month time-point and then reduced to near pre-injury levels over time following injury. The pattern of importance of Factor 2: Self-actualisation was seen to decrease over time following injury.

These differences in importance ratings across the factors and time-points following injury, point to the value of importance ratings in the TBI population following injury. In addition, QOLI Factor importance scores have provided insight into the basic order of importance of the factors within the TBI population. The variation in particular factor importance scores over time provides useful insight into the course of the relative importance participants assign to domains of SQOL over time following TBI. As such, it is considered prudent not to disregard importance scores and rely entirely on satisfaction scores in considering SQOL within the TBI population, particularly in longitudinal outcome research.

The inter-correlations between QOLI Total and Factor scores over the time-points following injury, showed the strength of relationships between the factors over time. The QOLI Total scores were all significantly correlated, no relationship reached 50% of shared variance. In general, scores at adjacent follow-up points provided strongest relationships in corresponding factors. The inter-relationships between three-month scores and six and twelve month scores were somewhat stronger than pre-injury and one month scores. Moderate relationships were identified between pre-injury estimates and later QOLI scores. QOLI Factor scores were also significantly correlated across the time-points, mainly in the range of 25% to 40% shared variance.

It is interesting to note the relative strength of the relationships between the factor scores and total scores across the time-points. For example, relatively weak relationships were noted between the pre-injury factor scores and the total score at twelve months post-injury (r = .30 to .49), compared with the stronger

relationships between the factor scores at the three-month point and total score at the twelve month data collection (r = .43 to .59). This suggests the three month time-point may be have an important role in predicting later outcome following injury.

6.7.1 Limitations and directions for further research

This study examined longitudinal SQOL outcome following TBI using both cross-sectional and longitudinal samples. In contrast with the cross-sectional sample that contained several hundred participants, the size of the longitudinal sample was relatively small. Although the longitudinal samples followed similar patterns of scores to the cross-sectional samples over time, this may have been a factor in the non-significant results found between time-points for the longitudinal sample.

It was very difficult to gain the compliance necessary from participants to complete assessment at each of the five time-points of the study required to join the longitudinal sample. Factors related to participants' willingness and ability to complete all the assessments at the required times may have in itself added confounding bias to the longitudinal sample, compared with the cross-sectional sample. Both cross-sectional and longitudinal samples were generally representative of the TBI population across demographic and injury variables.

Adjacent time-point analysis was used as a further check on the significance of outcomes over time and investigated the issue of possible differences between participants attending early time-points and not returning data at later time-points of the study. Independent samples t-tests compared QOLI scores for participants who returned surveys at both adjacent time-points

(e.g. Pre-injury and 1 Month, 1 Month and 3 Months etc) and those participants who returned data at only the first of the adjacent time-points (e.g. Pre-injury but not 1 Month, 1Month but not 3 Months etc). No significant differences were found on QOLI Total scores between participants returning data at both adjacent time-points and those who attended only the first time-point across the data points of the study, indicating there was no significant differential drop-out related to SQOL rating amongst this cross sectional sample.

Despite the small sample size, there were only minor differences between the cross-sectional and longitudinal samples for age, years of education and estimated pre-injury IQ, using the National Adult Reading Test. These demographic and clinical variables were generally representative of the TBI population as described in other epidemiological research by Hillier et al. (1997) and Tate et al. (1998). The proportions of severity of injury amongst the samples were more closely approximated the results of Tate et al.'s (1998) study, (58% mild, 20% moderate, 22% severe TBI). Hillier et al.'s (1997) study reported a greater proportion of patients presenting to hospital in South Australia with mild TBI (82% mild, 9% moderate, and 9% severe TBI). In both samples, in the present study there were few participants recruited with Extremely Severe TBI.

There are likely to be a number of other factors involved in this pattern of scores observed in the present study over time following injury, including demographic, and clinical aspects as well as physical, emotional, cognitive and social functioning following injury. For example, it is interesting to note the similarity in the proportions of the participants' severity of injury (as measured by duration of PTA), for the cross-sectional and longitudinal samples. About half the

sample in each case suffered a mild TBI, with PTA less than one hour. People with mild TBI are generally expected to fully recover from post concussive symptoms within three to twelve months following injury (Carrol et al., 2004). However, participants suffering more severe TBI may take longer, or may never return to pre-injury levels of functioning (Ponsford et al., 1996). This association between recovery of SQOL and the severity of injury represents one of a number of important variable relationships that has been demonstrated to be related to recovery following TBI (Dawson et al., 2000). As explained in Chapter 3, conflicting evidence about the nature of the relationship between severity of injury and SQOL outcome has been presented in a number of studies (e.g., Brown & Vandergoot, 1998; Mailhan et al., 2005). Based on the review of the literature in Chapter 3, it may be hypothesised that the QOLI scores of participants with more severe injury may take longer to return to pre-injury levels. This hypothesis will be tested in the next study in this thesis. The next study will also explore the relationships between SQOL outcome using the QOLI with a number of relevant variables across the demographic and clinical, physical, psychological, social and cognitive domains outlined in Chapter 3.

In conclusion, this study found SQOL ratings were reduced at the one, three and six-month time-points following TBI compared with the US-based normative QOLI distribution. Compared with pre-injury estimates, reductions in SQOL were significant at one and three-months following TBI in a cross-sectional sample. Whilst this trend was seen in a smaller longitudinal sample, the reductions in scores were not found to be statistically significant.

A corresponding fall in factor satisfaction scores for Self-functioning and Self-actualisation domains, which together accounted for eight of the sixteen QOLI domains, appeared to provide the basis for this trend in QOLI Total scores. Separate analyses confirmed the usefulness of importance ratings, which may be considered valuable in understanding SQOL trends following TBI. In addition, strong inter-relationships between QOLI scores across the time-points of the study were observed. Pre-injury ratings also showed some significant relationships that weakened in strength over the three, six and twelve month data-points.

In summary, Studies 2 and 3 have used the QOLI as a measure of SQOL to establish the distribution of pre-injury estimates, and investigate cross-sectional and longitudinal outcome following TBI. These preliminary studies have also provided a factor structure for the QOLI in this clinical sample, investigated the trends in outcome and demonstrated the relationships of these factors over time following TBI. The correlations between factor scores suggest the importance of early SQOL ratings on the QOLI in predicting later SQOL outcome.

It is likely that many variables influences this pattern of fall and recovery in scores following TBI. Further research is required to examine the effect of these variables on QOLI Total and factor scores following TBI. With this reference information now established, the next study (Study 4) will investigate the relationships and effects of a comprehensive array of demographic, physical, psychological, cognitive and social variables on SQOL outcome. This will lead to identification of models for predicting SQOL outcome following TBI (Study 5).